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Abstract

The purpose of the thesis is to illuminate the meaning of quality nursing care in the three major inpatient cancer care centres in Cyprus as seen from the standpoint of patients with cancer, patients' advocates and nurses. The data are based on: a) interviews (narratives) with 25 patients with cancer and two focus groups b) a focus group with patients' advocates and c) interviews with 20 nurses working in the cancer care departments.

The rationale for this study echoed a conceptualisation problem among patients, nurses and patients' advocates in relation to quality nursing care. The different interpretations held by the informants around this issue often creates problems of communication and understanding between nurse-patients and between nurses-patients' advocates. It also prevents a commonly shared concept to be adopted in the clinical setting.

In order to investigate this issue, a philosophical approach was adopted based on the philosophy of Paul Ricoeur and using the "lived experiences" of the informants as the basis of the investigation. The data were analysed using a hermeneutic phenomenological approach based on Ricoeur's interpretation theory but modified to suit the nursing paradigm.

What stands out from the study is the overlapping of the patients', patients' advocates and the nurses' experiences of quality nursing care. Based on the attributes that the informants have used to interpret the concept of quality nursing care, a shared understanding of the concept materialised. This shared understanding formed the basis for developing a theory of quality nursing care. Simultaneously, the study reinforced the importance of "getting the basics right" for providing quality nursing care to patients with cancer. Based on the informants' lived experiences, a set of guidelines of best practice were developed, as a means for influencing nursing practice.

**Listening to the voices of patients with
cancer and their nurses: a hermeneutic
phenomenological approach to Quality
Nursing Care**

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(A.C)**

Doctor of Philosophy

Middlesex University

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Use of the first person

I use the first person singular throughout this thesis. In so doing, I contradict the convention associated with positivist and natural scientific research, wherein the use of the third person is used to indicate objectivity; and acknowledge, in a manner that is congruent with the hermeneutical underpinnings of this study, that I as researcher am an important actor in the study. My use of the first person conforms to common practice in qualitative research, and is supported by Webb (1992).

Use of language in relation to cancer

I use the term “patients with cancer”. I am aware of the debate that is taking place around the most appropriate use of language. Indeed some of the language may raise issues of labelling or stigmatising. The fact that in the Greek language the term “patients with cancer” – *astheneis me karkino*, appeared to be more acceptable by the patients and their relatives instead of the term “cancer patients”- *karkinopatheis*, which is considered highly discriminating and labelling, played a decisive role in which terminology to use. Furthermore, another reason was the hermeneutic phenomenological nature of this study. This philosophical approach acknowledges the individuality of the person and his/her ontology.

Advocate’s role

An advocate is defined as “someone who pleads a case on someone else’s behalf” (Concise Oxford Dictionary, 2002). For the purpose of this study I identified this role in light of members of the cancer patients’ associations helping the patient to get all the necessary information to make decisions and having their rights protected. The patients and their relatives often considered that they were being asked at times to make very difficult decisions regarding treatment options and they felt that they lacked the necessary information to make these decisions. Furthermore, at times they believed that they were not given all the treatment options or their full rights explained.

PART 1

4

CHAPTER 1

INTRODUCTION TO THESIS

Background and rationale for the study

The difficulty lies, not in the new ideas, but in escaping the old ones, which ramify, for those brought up as most of us have been, into every corner of our minds.

(John Maynard Keynes cited by Drexler 1987)

Members of our society have different thoughts and role expectations about these phrases, (nursing care, therapeutic care, caring for others, and related expressions)); in relation to the kind of care they receive from nurses.

(Dr. Madeleine Leininger 1985)

The work described in this thesis addresses two central issues which in an implicit way echoed the above statements. The first issue concerns the exploration of the meaning of a complex and nebulous concept, that of quality in nursing care in the specific context of nursing in Cyprus. This context is characterised by escalating costs, the nation's population aging, technology increasing, and the already limited financial resources declining. As a result, multiple stakeholders are searching for ways to maintain or enhance quality and nursing care is seen as the cornerstone for providing this care. The second issue comes as a response to enhancing quality and it constitutes an attempt to influence practice through the new knowledge that has been gained. This is done through the development of quality care guidelines for cancer nursing.

This study arose as a response to a particular health care context in Cyprus which lacked a specific definition or a theory of quality nursing care, clinical standards, specific policy and strategic planning of nursing services. The nursing profession was subsumed under medicine; and nurses in Cyprus were struggling to attain their professional identity. Nursing practice was prescribed by others and highlighted by traditional, ritualistic tasks with little regard to rationale. A growing body of literature asserts that conceptual

models and theories could create mechanisms by which nurses would communicate their professional convictions, provide a moral/ethical structure to guide actions, and foster a means of systematic thinking about nursing and its practice (McEwen 2007; Chinn and Kramer 2004). Echoing this belief, it is hoped that through this study new knowledge can be developed by interpreting the concept of quality nursing care which can adequately support a series of quality care guidelines for cancer nursing in Cyprus but also for the international nursing context. This is achieved by taking a holist approach to the issue, hence exploring the views of the patients, nurses, and key advocates.

Hermeneutic phenomenology formed the conceptual and methodological framework of this research. The decision for this approach was led by the fact that the inquiry into the nature of the quality of nursing care constitutes both an ontological and epistemological venture; it is the study of the nature of nursing and of nursing knowledge.

Why hermeneutical? The meanings of “quality nursing care” and the practices that improve or obstruct its provision are expressed in narrative interviews and focus groups, which were tape recorded as well as written down, therefore producing texts that could be interpreted. Therefore, the research method needed to be hermeneutical.

Why phenomenological? When patients and non-patients informants talk about the provision of quality nursing care, they are themselves interested in the good or bad practices in these situations. As a researcher I wanted to understand the practices as these were expressed in the narratives and focus groups. The narratives and the focus groups are about these specific practices. It is not the texts that are the subject matter to be investigated, but the perceptions (lived experiences) expressed in them.

This philosophical paradigm also informed the specific approach to the topic under investigation; that of exploring quality nursing care. The idea that was expressed by philosophers such as St. Augustine, Schleiermacher, Heidegger and Ricoeur that the part must always be understood in the light of the whole guided my decision to focus on quality nursing care (=part) which is a constituent of health care quality (=whole). In

order to reach to an understanding of this concept in terms of this study, quality is discussed in its wider health care context and not merely in relation to the nursing context which remains the main focus of this study. This approach becomes according to hermeneutic phenomenology a “legitimate” way of understanding things.

Through this thesis the concept of quality nursing care has been analysed (=interpreted) through the lived experiences of the informants. Before this study, even though the health services and the nursing division of the Cyprus MoH (Ministry of Health) were referring to quality and quality nursing care respectively this was done without a specific interpretation being proposed or used. Therefore, this concept was used with an elusive context, open to various interpretations and understandings. This is hardly a national problem, but it rather troubles nursing world widely as the concept has been over conceptualised leading often to confusion. Therefore, analysing or interpreting a concept as this study aims at, helps “to clarify overused, vague, concepts... so that everyone who subsequently uses the term will be speaking of the same thing” (Walker and Avant, 1983, p27). By analysing a concept, it “becomes useful and meaningful in the discipline... a critical step in the process of developing knowledge related to concepts of interest in nursing” (Rodgers, 2000, p.84). Moreover, it is widely believed that use of theory offers structure and organisation to nursing knowledge and provides a systematic means of collecting data to describe, explain, and predict nursing practice. Theories make according to McEwen (2007) nursing practice more overtly purposeful by stating not only the focus of practice, but specific goals and outcomes. Theories define and clarify nursing and the purpose of nursing practice to distinguish it from other caring professions by setting professional boundaries. Finally, use of a theory of nursing leads to coordinated and less fragmented care (Chinn and Kramer 2004; Alligood and Tomey 2002).

Quality health care

Health care quality in the UK as elsewhere in the world remains a major issue in the 21st century as it had been in the latter part of the 20th. In the 1970s, the focus was on improving quality (Johnson and McCloskey 1992), whilst by the 1990s the focus was on

preserving quality (Hogston 1995). Nowadays the focus is being redirected back on improving quality (Strandberg et al. 2006). This change has resulted in an emphasis on monitoring quality, on developing quality, and on defying outcomes that can serve to as quality monitors. These changes stem from concern about the effects of cost-containment efforts on the quality and accessibility of health care services.

A part of these changes has been the shift in quality efforts from structure and process indicators to outcomes of care. According to Van Maanen (1984, p18), structure is the evaluation of the organisation of the institution delivering care; the conditions under which care is provided and its impact on quality, i.e. buildings, budget and equipment. Process concerns the evaluation of the performance of health professionals in the management of patients, and the outcome is the evaluation of the end result, observable changes in the health status of the patient. Strom (2001) and Mackay and Risk (2001) stressed that in the past, health organisations have concentrated on establishing QA (Quality Assurance¹) programmes according to the structural standards of the particular institution. Gradually, there has been a shift to greater emphasis on the process of patient care in the areas of patient assessment, teaching and discharge planning. Additionally, documentation of each step in the process became critical evidence to the demonstration of the provision of quality care.

The concept of quality as an indicator of both the effectiveness and efficiency of professional nursing practice is an issue dominating the National Health Systems, the professional nursing bodies, and international organisations today (OECD 2004a; 2004b; ICN 2007). The health care reforms that have swept through the UK NHS as a consequence of the White Paper “Working for Patients” (DoH 1989) and more recent papers such as QOF-Quality and Outcomes Framework (DoH 2004a), A Strategy for NHS Information Quality Assurance (DoH 2004b) have ensured that quality, quality of care, standards of care, quality indicators and quality assurance have become familiar language in the UK NHS.

¹ Quality assurance (QA) refers here to an organised process that assesses and evaluates health services to improve practice or quality of care (Fowler 1990).

The UK experience on quality issues is of particular importance to Cyprus mainly for two reasons. Firstly, the British occupancy of Cyprus occurred at a period of time when the structures of the Republic of Cyprus were developing, influencing the process. As part of this process they organised the health care system of the island based on the model they had used to structure the UK NHS (Anastasiou 2000). Secondly, the MoH and the independent health care specialists that structured the new National Health Insurance Scheme (NHIS) based their recommended amendments and proposals having as an example the UK NHS (Polyneikis 2006; Polyneikis and Kalos 1992).

Quality of nursing care

Any attempt to improve the quality of nursing care must begin with a definition of the term quality nursing care. However, there are probably almost as many definitions of quality nursing as there are nurses. Different definitions for quality nursing care have been introduced in the public sector, the private sector (Normand et al. 2002) and more recently by patients themselves (Radwin 2000). This view is strengthened by Gunther and Alligood (2002, p354) who assert that “the definition of quality from different perspectives varies: society judges utilitarian benefits, payers the economic outcomes, patients the personalised attention received, and providers the congruity with professional worldviews and standards”. They assert that two main distinct, although complementary, frames of reference exist within the process of evaluating and defining the quality of nursing care which this study will address in its quest for interpreting the term: (1) that of the patient and (2) that of the nursing profession.

Even though much has been written about the phenomenon of quality, significant variations exist in its interpretation and use, “unaware or undeterred by the conceptual confusion, quality care continues to be assured, controlled, evaluated and managed in Health Service Today” (Attree 1993, p355). The literature review for this study revealed a gap, which the existing definitions failed to incorporate the views of patients and nurses in a single definition something which this study will aim at. These conceptualisations of quality nursing care will be further discussed in chapter 3.

In relation to the Cyprus context, it is my assumption that the nurses are not sufficiently and efficiently trained to evaluate and improve quality which is a fundamental constituent of health care. However, I would argue that the nurses are not to be blamed for this lack of appropriate education as the roots of the problems need to be identified in the health care system's nature instead. There is a lack of clinical guidelines, standards and quality indicators through which quality nursing care could be achieved and assessed. Moreover, health services heavily rely on outdated quality indicators such as the waiting lists (Martin et al. 2003), and the 5 D's-Death, Disease, Disability, Discomfort and Dissatisfaction (Korniewicz and Duffy 2003). These aspects have created a situation where quality assurance remains as a back stream.

Furthermore, it is assumed that cultural beliefs, health perceptions and attitudes play an important role as to the way Cypriot patients and nurses respond to health, illness, and death as well as how they define quality and quality nursing care. However, often these fundamental aspects of care are overlooked or undervalued by the nurses and other health care professionals.

Politics is an essential component when it comes to the provision of health care and most importantly quality health care which often requires additional funds. Whilst the Cyprus HCS (Health Care System) (public sector) remains funded directly by the state budget, from general taxes, politicians play a key role in health matters. Politicians have the monopoly assigned to them by the Constitution to shift the funding to where they wish and think it would be best for the public. In anticipation of the full deployment of the NHIS in 2010, this situation is likely to remain unchanged. However, its introduction was probably the boldest decision taken by the Cypriot parliamentarians (Cyprus Government Gazette 2001).

The Cyprus healthcare system: a system in transition

Health care delivery in Cyprus as elsewhere in the world is experiencing unparalleled changes ...and reforms need to be applied yesterday [...]

(Opening Speech at the Parliament by the Minister of Health, 2006)

Important events are currently taking place which affect Cyprus mixed HCS. Such events include the increased levels of taxation, the effects of Cyprus membership in the EU (European Union), the high level of contact with the National Health Service and its involvement into NHIS which initiated an extensive debate about legislation and individual rights. These events resulted in the Cypriot population becoming more concerned about the type of health services that are provided, the level of resources that are or should be spent, and most importantly the level of quality of care they receive. The MoH has not responded to the peoples' worries and as a consequence the issue of quality of care did not receive any systematic debating. In 2007, in Cyprus there was no coherent national strategy which addresses the issue of quality. As a response, in order to protect their rights and press for better care patients with cancer have established two cancer associations.

The increased demand for health care services, the innovations in the treatment of diseases and the escalating cost of care are creating momentous changes in systems of health care delivery (Golna et al. 2004). In the light of such pressures and experts' suggestions, health care reforms in Cyprus began slowly to take place in the mid to late 1990s. The reforms commenced following the recommendations made in the reviews of the MoH by the Nuffield Institute for Health (1994, 1998) and the report by Hsiao and Jakab (2003). In the Nuffield Institute report, the MoH is described as operating on the basis of a division between three basic functions: administrative, technical, and operational. Such a simple and divisive system, based on a fragmented ministerial system, was characterised as inappropriate to modern systems of management (Nuffield Institute for Health 1998). According to the latter study which investigated the costs of the NHIS prepared in July 1993, the law left several key points ambivalent that could impair achieving the original intent of the NHIS (Hsiao and Jakab 2003; Hsiao 1997).

Furthermore, the need to harmonise the health care services with the European regulations prior to Cyprus' accession to the EU in 2004, led the MoH to adopt a strategy for reorganising the health care delivery system. The introduction of the reforms

resulted in a different management approach, which is a component of this study as it affected the way nursing was organised and delivered in the Public Sector² and also led to the decentralisation of services. The reforms also brought the independence of the nursing services division, which previously was under the authority of the medical services. Patients and the public however, viewed these reforms with scepticism. Despite the reassurance given by government officials, the changes give the impression that they were introduced for the sake of the harmonisation process and the suggestions by the foreign experts rather than a decisive measure to improve the accessibility, delivery and quality of the care.

In order to ensure that the people of Cyprus will receive, quality nursing care, nursing must take an active role in determining how these goals are achieved. The need to define quality of nursing care and to determine how it is measured is now more than ever before a necessity rather than a luxury. However, these actions need to be made both for the public and private systems of care. Their parallel operation has resulted in duplication and waste, a point also mentioned in the Nuffield report on Cyprus' health care. The fact that the private sector receives no funding from the government means there is little continuity of care between the private and public sectors, and poor communication between health professionals and this has the potential to impact significantly on the quality of health care (Antoniadou 2005).

European and Cyprus cancer statistics

With almost three million cases and almost two million deaths in 2004, cancer remains an important public health problem in Europe, and the ageing of the European population will cause these numbers to continue to increase even if age-specific rates remain constant (Boyle and Ferlay 2005). Lung, colorectal and breast cancer represent the three most common incident forms of cancer, accounting for two-fifths of the total European cancer burden. Lung, colorectal, stomach and breast cancers account for nearly half of all cancer deaths in Europe. As in the case of the EU, for Cyprus cancer remains a major cause of morbidity and has been identified as a major public health

² See appendix B-Diagram 1

issue affecting one in four of the population (Cyprus Statistical Service-CSS 2003). A detailed statistical presentation of the problem of cancer in Europe and in Cyprus will be presented in chapter 3.

Ethnohistory, cancer care and nursing context in Cyprus

As this study is about a specific ethnic group, that of Greek-Cypriots, the ethnohistory of Cyprus becomes essential for this study. Ethnohistory is important because defining quality can be a fruitless debate because quality is socially constructed and influenced by individual values, beliefs and attitudes whilst anthropologists support that culture might also influence quality (Davies et al. 2000; Koch 1992). Most anthropologists define culture as the shared set of implicit and explicit values, ideas, perceptions, concepts, and rules of behaviour that allow a social group to function and perpetuate itself (Hudelson 2004, p345).

Therefore, the cultural background of the informants and myself as well as the nursing context are important considerations as it is now agreed that these influence our beliefs, behaviours and attitudes to health and illness as well as the perceptions of the services we may use (Papadopoulos 1999a). Leininger (1995) supports the position that cultural values are critical elements in nursing because they greatly affect human behaviour and action modes. Understanding the cultural beliefs and values of the patients becomes a means to developing sound and reliable nursing care plans and decisions about nursing practices. The nursing context in Cyprus presents many particular characteristics which needed to be taken into consideration as part of this study. Nursing is a profession that has remained under the authority of the medical profession for many years. This negatively influenced nurses and the image of nursing in Cyprus. Therefore, nursing nowadays struggles to restore the image of nursing and specifically to disengage from beliefs such as that nurses are the physician's "handmaiden", that the role they play in the care of the patient is negligible and that they have minimum education. Nursing needs to attain its professional identity, and to do this the introduction of new knowledge, theories and conceptual frameworks are needed. These are the means by which the separation from the medical profession can be completed and established and

nursing can thrive as a unique discipline. However, these particularities of nursing in Cyprus are discussed in more detail in chapter 4.

The Cypriot society is a mixture of both European and Middle Eastern characteristics, reflecting the many conquerors that have occupied the island throughout time (Pantelidou and Chatzikosti 2003). Healthcare and the role of the patient reflect the strong ethnic elements of the Cyprus culture which considers cancer as a taboo topic. Cultural beliefs and customs affect the population's perception of health and illness, and determine patients' willingness to monitor and manage their disease. The collective and patriarchal nature of Cypriot culture has restricted major changes or transformations to cultural norms, traditions and values which relate to health and illness.

Aims, Objectives and Assumptions of the Study

The aim of the study is to investigate the views of patients with cancer and to explore their experiences and needs in terms of quality of nursing care in the cancer care departments in Cyprus. In the light of the patients' views, the views of the nurses providing care to these patients, and the views from the cancer associations will be explored.

What assumptions are made by this study?

- That nursing quality has not been explored in Cyprus from the perspectives of both nurse and patient.
- That the patients' and the nurses' perceptions have not previously been compared.
- That there are both differences and similarities in the patients, nurses and key advocates' perceptions of what constitutes quality nursing care.
- That nursing quality can be improved in cancer care departments.

In order to provide empirical evidence of these assumptions three research questions are formulated as a focus for investigation:

- What are the perceptions of the patients, the nurses and the key advocates on quality nursing care?
- What is the nursing response to the patients' views on quality nursing care?

- Are there any common principles in relation to quality nursing care among nurses and patients?

MPhil objectives

- Reviewing the literature and identifying the recommended quality indicators for providing quality nursing care.
- Investigating the perspectives of patients, nurses and key advocates about quality nursing care and from these propose an interpretation of “quality nursing care”.
- From the above, provide conclusions and recommendations to the MoH.

PhD objective

To produce quality care guidelines for cancer nursing in Cyprus underpinned by a theory of what quality of nursing care is in relation to the Cypriot context.

Outline of the thesis

The thesis is presented in five parts. Part one is the introduction to the thesis. The background of the study is discussed in relation to the Cyprus context which is analysed in some depth. The concepts used by this study are also analysed in detail.

Part two outlines the theoretical context of the study. It contains three chapters. The first discusses hermeneutic phenomenology, which forms the conceptual and methodological framework of the research; the second reviews aspects of quality in the Cyprus healthcare system and evaluates it in terms of the purposes of this study and the third chapter comprises an ethnohistoric review on Cyprus. Furthermore, the issues underpinning quality within Cypriot society and culture and how these may affect people's attitudes, perceptions, beliefs and values towards health are explored.

Part three of the thesis, describes the empirical phase of the research and includes two chapters. The first chapter describes the methodological decisions and approaches to the study and the second chapter presents and discusses the findings of the study.

In part four, the product of the thesis is presented in the form of nursing quality care guidelines for clinical practice underpinned by a theory of what quality of nursing care is.

In the last part, the research is evaluated providing suggestions for further research.

PART 2

CHAPTER 2

HERMENEUTIC PHENOMENOLOGY³

A theoretical framework for the study

Hermeneutic phenomenology forms the methodological and conceptual framework of this study. This chapter gives an account of the development of hermeneutics in both its early and modern phases. I especially draw on the tradition of hermeneutics i.e. the tradition of text interpretation, as it first emerged in protestant theology and then became a powerful tradition within philosophy and human studies, thanks to the works of Schielermacher, Dilthey, Heidegger, Gadamer and Ricoeur.

The chapter begins with a discussion of the etymology of the word “phenomenology” and “hermeneutics”. This is followed by an outline of the discipline in its early phase. Next, the development of modern hermeneutics is traced through a review of the work of five major thinkers: Schielermacher, Dilthey, Heidegger, Gadamer and Ricoeur.

This study is based on the philosophy of Paul Ricoeur for its methodological and conceptual framework. Ricoeur’s philosophy is according to Simms (2004, p2) simultaneously a philosophy of life and a philosophy of reading enabling “it to be universally applicable: whatever discipline we are in, be it history, psychoanalysis, literary criticism or whatever, that discipline is constructed through texts, and those texts each in different ways conceal their true meaning that hermeneutics reveals-the meaning of life”.

Ricoeur was a French philosopher best known for combining phenomenological description with hermeneutic interpretation. As such, he is connected to other major hermeneutic phenomenologist, Heidegger and Gadamer as well as with Dilthey. Ricoeur’s hermeneutical approach aligns with the ontological (interpreter) and epistemological (interpretation) concerns of this study which will be discussed later in this chapter.

³ In Greek- *Ερμηνευτική Φαινομενολογία*

The inclusion of this chapter was considered essential for the aims of this study. The most important arguments that underpin my decision to include this chapter are outlined here:

- The reader through this chapter is familiarised with the philosophy of hermeneutics, the notions and language that belongs to it. Through this familiarisation I aim at an appreciation of philosophy as a methodological approach.
- This study is based on the “lived experiences” of informants. The notion of lived experience was the basis and perhaps the most important contribution of Dilthey to modern philosophy. This notion has been adopted by his successors and most importantly, Ricoeur.
- Dilthey, Heidegger, Gadamer, and Ricoeur all have written about the importance that history and historicity play in the way we acquire our understanding of things (including the lived experience). Historicity also reflects the notion of culture and this aspect has informed my decision to include a critical review of Cyprus ethnohistory in the study.
- The philosophical approach of Ricoeur informed the decisions taken during the empirical phase of this study.
- References to earlier hermeneutics are considered essential in order to understand the source of some of the ideas that Ricoeur has adopted and developed in his philosophy.

It is difficult to understand the meaning of “hermeneutics” and “hermeneutic phenomenology” or the notions related to these terms unless the etymologies of the words are appropriately explained. In view of the fact that these notions appear

frequently in the study it was considered necessary to provide the etymological explanations given to these notions.

The concept of hermeneutics

Hermeneutics, which is mainly philosophical in nature, has been defined as the theory and practice of interpretation and understanding (Urmson and Jonathan 2005). The term “hermeneutics” comes from the Greek word *hermeneuo* translated to “interpret” and the noun *hermeneia*, “interpretation” (Palmer, 1969). In Greek mythology, Hermes⁴ was the mythical Greek God, also known as the messenger (Jost and Hyde 1997). Dermot (2006) argues that “Hermes was a go-between between gods and humans, who tells lies as well as truths, who misleads as well as leads. Hermes represents the untrustworthy yet necessary link between worlds” (p271).

In its original use, for a long time its exclusive use, hermeneutics stood for the principles of biblical genesis. However, it was in the work of Heidegger that it gained a whole new meaning. “Hermeneutics” held a central place in the phenomenological study he has embarked upon (Clark 2005).

The concept of phenomenology

The Greek word “*φαινομενολογία*” (phenomenology) consists of two constituents, the word “*φαινόμενον*” (fainomenon) and the word “*λόγος*” (logos). The Greek word *φαινόμενον*, to which the term phenomenon refers to, is the verb *φαίνεσαι* (fainesai), which signifies according to Moran and Mooney (2004) ‘*to show itself*’. Therefore, *φαινόμενον* means that which shows itself, the manifest.

“Φαίνεσαι” (fainesai) itself is a middle-voiced form which comes from φαίνω-to bring to the light of day, to put in the light. Φαίνω (faino) comes from the stem φα-like φώς, the light, which is bright – in other words, that wherein something can become manifest, visible in itself” (Moran and Mooney 2004, p279).

Accordingly, the *φαινόμενα* or “phenomena” are the totality of what lies in the light of the day or can be brought to the light – what the Greeks sometimes identified simply

⁴ In Greek-*Ερμής*

with τα ὄντα (ta onta -the entities). The other half of the Greek etymology of phenomenology is the word - λόγος (logos⁵) as Heidegger argues (1962, p49-63). The proper meaning of this word, Heidegger argues, has been concealed in the history of philosophy. It is interpreted as positing or judging and thus as reason, judgement, conceptuality, definition, ground, or relation. For Heidegger, on the contrary, “logos” is not primarily to be understood as judgement, but as “*letting something be seen*”; a “logos” is “*a making clear*” of something (Heidegger 1962, p49-63).

Moran and Mooney (2004) assert that the basic signification of logos is “discourse”, and that word-for-word translation will not be validated until we have determined what is meant by “discourse” itself. Moran and Mooney (2004, p282) argue that the later history of the word logos covered up the real signification of “discourse”, and especially by the numerous arbitrary interpretations which subsequent philosophy has provided.

The early phase of hermeneutics

The roots of hermeneutics are lost back in ancient times and particularly ancient Greece. Plato (427BC-348BC) was probably one of the first philosophers that used hermeneutics in his attempt to comprehend religious issues (SEP-Stanford Encyclopaedia of Philosophy 2006a). Dermot (2006) comments that “the principles of interpreting were gradually set down in ancient and medieval attempts to interpret sacred texts, for example in the Biblical schools of Alexandria where Judaic and Hellenic learning intertwined” (p271).

Philo of Alexandria (20BC-50AD), a Hellenised Jew, and later Origen of Alexandria (185AD-254AD) are considered by Dilthey (1860) amongst the first figures that actually applied hermeneutics in practice. Philo believed in the allegorical meaning of the Old Testament and claimed that literally interpreting the scripts might result in losing the concealed deeper meaning which may only be uncovered through systematic interpretation (SEP 2006a). This allegorical meaning was later termed as a “multiple meaning” problem by Ricoeur. According to Ricoeur (1976) this problem designates a

⁵ (literally meaning ‘speech’, thus lexi – λέξιη - meaning ‘the word’)

certain meaning effect, according to which one expression, of variable dimensions, while signifying one thing at the same time it signifies another thing without ceasing to signify the first. He asserts that “in the proper sense of the word this is the allegorical⁶ function of language” (p62).

Another influential figure both of his time and for modern philosophy is St. Augustine (354-430). His writings had a great impact on the way hermeneutics were further developed by Dilthey, Heidegger, and Gadamer (SEP 2006a). St. Augustine’s *On Christian Doctrine*⁷ puts forward principles of exegesis for the Bible and is considered as one of the fundamental texts of hermeneutics, and one which had a strong influence on Heidegger. According to Dermot (2006, p272) the most important principle identified in St. Augustine’s ‘On Christian Doctrine’ was “that the part was always to be understood in the light of the whole, and thus a sentence taken from the Bible must always be read in context”.

It does not take much effort to identify the influence of these principles in the hermeneutic philosophy developed by Heidegger. The first principle for example suggested by St Augustine that the “*part was always to be understood in the light of the whole*” holds a fundamental place in Heidegger’s idea of the “whole and parts”. According to Heidegger, it is only through the movement between the parts and the whole that understanding can be achieved (Heidegger 1962). The movement between part and whole in the process of interpretation later became known as the hermeneutic circle (Coltman 1998). Despite the differences of these writers in the way that the Scriptures should be interpreted, they shared a common idea, a focus on interpreting textual material.

The works of the philologists Friedrich Ast (1778-1841) and Friedrich August Wolf (1759-1824) are considered to be the preparatory work based on which Schleiermacher developed his theory on hermeneutics (Palmer 1969). They share many common ideas as well as differences. Their mutual perception is that explanation must be grounded in

⁶ *All-egoreo*: while saying one thing to say another thing

⁷ *De doctrina christiana*, c. 396-427

understanding and that, understanding should in any case be distinguished from explanation and this holds a central place in their work.

Romanticist⁸ Hermeneutics
Friedrich Schleiermacher

“Hermeneutics as the Art of Understanding does not exist as a general field, only a plurality of specialised hermeneutics”

(Schleiermacher as cited by Palmer 1969, p84)

Schleiermacher and his follower Dilthey are the main proponents of romanticist hermeneutics. According to Demeterio, (2001, p1) both of them were heirs to a very dominant philosophy of the subject initiated by the French scientist, mathematician, and founder of modern philosophy Rene Descartes (1596-1650). The period of romantic hermeneutics was dictated by the interest in the human sciences and the eagerness to guard their integrity as distinct from the natural sciences (Demeterio 2001). Scholars of this period were also concerned with interpreting the old texts such as the Old and the New Testament. These are the twin pillars on which modern hermeneutics is built. What made Schleiermacher a pioneer of his time was his achievement “to unite the intellectual currents of the time so as to articulate a coherent conception of a universal hermeneutics, a hermeneutics that does not relate to one particular kind of textual material, but to linguistic meaning in general (SEP 2006a, p3).

Schleiermacher (1768-1834) has been considered the father of contemporary hermeneutics (Grondin 1995). His work became known through a series of lectures, according to Moules (2002), which gave his perspective for a general hermeneutics as the art of understanding, and his early account of the hermeneutical circle. Contrary to the philologists that were his immediate predecessors, who believed that hermeneutics was determined by the content of what was to be understood, Schleiermacher, according to Gadamer (2006)

⁸ The term romanticism was a literary, artistic, and cultural movement during the 18th and 19th century, within which Schleiermacher belonged.

“No longer seeks the unity of hermeneutics in the unity of the content of tradition to which understanding is applied, but rather he seeks it, apart from any particular content, in the unity of a procedure that is not differentiated even by the way the ideas are transmitted—whether in writing or orally, in a foreign language or in one’s own” (p179)

Schleiermacher wanted hermeneutics to be expanded to a more general understanding of texts and not a specialised one, such as had existed heretofore in philology and theology. Schleiermacher took as his starting point the process of understanding as it occurs in the case of the written word. He thus emphasised that interpretation of a text had to take place along two different axes: grammatical and psychological (Dermot 2006). The psychological rudiment entails that we must be able to get inside the mind-set of the author. Consequently, the psychological rudiment constitutes according to Mueller-Vollmer (1997) a source of evidence from which assumptions about the author might be drawn. However, there is also a grammatical rudiment to the text, which is related to the language used by the author to express his thoughts and ideas. Therefore, we must also “be familiar with the language as it was used at the time the text was written” (Dermot 2006, p275).

An aspect of Schleiermacher’s philosophy of hermeneutics involved the emotional engagement with the text and consequently with the person that wrote the text, “to the point that one transforms oneself into the other” (Wilson 1989, p157), in order to grasp the original lived experience. Therefore, for Schleiermacher, the process of understanding was essentially a reconstructive process through which the interpreter entered into the psychic life of an author by way of the shared medium of language in order to re-experience his creative act (Drapper 1997). However, for this aspect of his work, Schleiermacher received criticism by later philosophers such as Gadamer who argues, “That understanding actually involves an irremovable distance. Distance is a necessary precondition for understanding, not something to be overcome; what is completely assimilated does not come into focus for understanding’ (Dermot 2006, p275).

One of Schleiermacher's most important contributions to hermeneutics is seen in his statement that "[...] complete knowledge always involves an apparent circle... each part can be understood only out of the whole to which it belongs, and vice versa" (Mueller-Volmer 1985, p84). He identified a concept that remained at the centre of hermeneutical theory, that of the hermeneutical circle. The hermeneutical circle was first described by Heidegger in *Being and Time* (1927). According to Heidegger as cited by Simms (2004) "as a consequence of understanding of existence being depended on understanding of the world and vice versa, any interpretation which is to contribute understanding, must already have understood what is to be interpreted" (p37). Ricoeur's position on what constitutes the hermeneutic circle differed than the one proposed by Heidegger. Ricoeur (1967) claims that "we must understand in order to believe, but we must believe in order to understand" (p351). The circle can also be understood in a different way "hermeneutics proceeds from a prior understanding of the very thing that it tries to understand by interpreting it" (Ricoeur 1967, p352).

The next development in hermeneutics to be considered here came in the latter half of the nineteenth century with the work of Dilthey.

Wilhelm Dilthey
Hermeneutics as the Method of the Geisteswissenschaften⁹

Alexander von Humboldt (1769-1859), Chajim Steinthal (1823-1893), and Friedrich Carl von Savigny (1779-1861) took over the task of continuing the work of Schleiermacher in relation to hermeneutics in a climate which was similar to its early years, rather than being new age for hermeneutics. Scholars were more concerned with the application of hermeneutics to the disciplines of theology, history, and law rather than focusing on the real task of hermeneutics, which is communication and understanding (SEP 2006a). Dilthey (1833-1911) is situated at this turning point of hermeneutics according to Ricoeur (1998).

⁹ *Geisteswissenschaften* – all the humanities and social sciences, all those disciplines which interpret expression of man's inner life. Also see Palmer 1969, p98.

According to Palmer (1969), Dilthey began to see in hermeneutics the foundation of the *Geisteswissenschaften*. He wanted to develop hermeneutics as the method for these social sciences in “contrast to the empirical method of the natural sciences-*Naturwissenschaften*” (Dermot 2006, p276). His argument was focused on the idea that in the natural sciences we seek to explain phenomena in terms of cause and effect; in contrast, in the human sciences we seek to understand. Dilthey’s declaration that “we explain nature, but man we must understand” describes the essence of his philosophy (Palmer 1969, p45). Dilthey describes two contrasting approaches to the acquisition of knowledge as “explanation” (eklären) and “understanding” (verstehen). West (1996) in his “*Introduction to Continental Philosophy*” differentiates the two notions brought forward by Dilthey:

“[...] Explanation, however, is not by itself an adequate model for human sciences, whose object of study is humanity itself. Human beings have a psychological existence and, to that extent, can be studied by the methods of explanatory science. But the human sciences are more concerned with the various expression of mind or spirit. The human sciences deal with actions, utterances, institutions, and artefacts which, unlike events, in the physical worlds, have intrinsic meaning and so call for a different cognitive approach. Understanding is concerned with the recovery of meanings rather than the identification of causal regularities. It is not concerned with generalization but with the description of the individual in its full complexity and particularity” (p83).

Dilthey was influenced by Kant’s “*Critique of pure reason*”, because Kant determines natural sciences to be the peak of objectivism. At the same time like Kant, Dilthey tried to realise objectivity for Human Science. Dilthey’s objective was to write a “*Critique of historical reason*” which would extend the Kantian programme to include the cultural sciences, and in which he would clarify the grounds for the claim to valid knowledge, and identify the methods through which that knowledge could be derived (Palmer 1969). He tries to construct human science in terms of natural science; because the object of Human Science is “Humans Who” having the dimensions of both the physical and mental. It does mean that the different objects constitute the centre of the difference of both sciences. We can investigate Human’s physical dimension as natural science (or positivism) but not the mental dimension. Thus Dilthey embraced history asserting that human individuals and societies can only be understood historically (Gadamer 2006).

Dilthey's aim of historicism is that the "historical diversity of human civilizations means that we must think ourselves into their categories in order to understand them" (Inwood 1991, p3).

What constitutes Dilthey's special importance and distinguishes him from the neo-Kantians is that he does not forget that in this instance, "*experience* is something quite different from what it is in the investigation of nature. In the latter, all that matters are verifiable discoveries arising from experience" (Gadamer 2006, p216). Therefore, the concept of lived experience (*Erlebnis*), the manner in which a life is lived historically, was Dilthey's central unifying concept. According to Palmer (1969), Dilthey defines an *Erlebnis* as a unit held together by a common meaning:

"That which in the stream of time forms a unity in the present because it has a unitary meaning is the smallest entity which we can designate as an experience. Going further, one may call each encompassing unity of parts of life bound together through a common meaning for the course of life and "experience" — even when the several parts are separated from each other by interrupting events" (p107)

However, Dilthey asserts that lived experience, as such, does not provide self-understanding. Self-understanding is obtained only to the extent that the self relates to itself as it relates to others. Dilthey, as cited by Palmer (1969), sets the limitations of the "lived experience" and at the same time lays down the foundations of the twentieth-century phenomenology:

"The way in which "lived experience" presents itself to me [literally, "is there-for-me"] is completely different from the way in which images stand before me. The consciousness of the experience and its constitution are the same: there is no separation between what is there-for-me and what in experience is there-for-me. In other words, the experience does not stand like an object over against its experiencer, but rather its very existence for me is undifferentiated from the whatness which is present for me in it" (p109).

Indeed, it was Dilthey's argument that we can understand human culture and history precisely because, like nature for God, they are expressions of life. Rickman (1990, p40) comments that this understanding, "is not an obscure intuition, a mysterious flash of

lightning, or a gimmick which replaces disciplined intellectual work and makes it superfluous but it is that which opens up to us the world of individual persons, and thereby also possibilities in our own nature”.

On the same topic, Palmer (1969) asserts that understanding is not a mere act of thought but a transposition and re-experiencing of the world as another person meets it in lived experience, an operation of silent thought which accomplishes a pre-reflexive transposition of oneself into another person (p115).

Dilthey influenced Heidegger, Gadamer and Ricoeur, who took the idea that a historically lived life is finite, and hence that cultural understanding can never be absolute science. Furthermore, they adopted the idea that understanding was not simply something which occurred on a backdrop of conceptualisation and explanation, but was an important and fundamental structure in human being or *Da-sein*, and as such occupied a central place in philosophy (Grondin 1995).

Martin Heidegger: The Hermeneutical Dimension of Being

“Is” is one of the most commonplace words in the English language. [...] It is difficult to speak, write or think without it. But few people ask – what is “is”? If we forget this basic question of being, we lose sight of the way we are in the world”

(Heidegger as cited in Appignagnesi 2005, p3)

A student of Husserl (1859-1938), Heidegger made some substantial choices, leading him to a different path that opened up a notable path in the history of hermeneutics with his influential work *Being and Time*¹⁰. Heidegger brought the ontology of the subject and the “*something*” which Husserl disclaimed back into the “*experience-of-something*” (Jardine 1994; Caputo 1987).

Heidegger’s primary concern was ontology, or the study of being (Clark 2005). As opposed to Husserl, Heidegger focused on what sort of knowing occurs when one is not

¹⁰ *Sein und Zeit*- Literally ‘existence’ and, often translated by its components, being-there.

outside the situation but is involved in it (Wilkes 1991). Heidegger propounded that an understanding of the person can not occur in isolation from the person's world and especially the unique knowledge acquired through everyday activity (Demeterio 2001). He referred to human existence as "*Dasein*" or "being-there" which stressed the situatedness of human reality (Walters 1995).

Heidegger's philosophy therefore views the experience as the person rather than something that happens to a person (Duke 1998). Heidegger claimed that in order for a question to be understood, who the questioner is has to be taken into account, as does who the questioner is when asking the actual question (Ree 1998). This idea is opposed to Husserl who sought a means of directly exploring consciousness and introduced the method of "*epoche*" by which judgments about reality are held in suspension or "*bracketed*" (Holmes 1990). Heidegger and Ricoeur dismissed the idea of bracketing; claiming that it is impossible to bracket one's "*being-in-the world*" in the process of philosophical enquiry and that it is only feasible that one can interpret something according to one's lived experience (Walters 1995).

In his work *Being and Time*, Heidegger criticised Descartes's dichotomy between mind and body in relation to "understanding" through the notion of being-in-the-world. Descartes had based the notion of understanding upon the premise that a distinction could be made between the mind, which existed in the dimension of time, and the body, which was physical in nature and occupied three dimensional spaces (Rorty 1986). However, according to Drapper (1997), Heidegger challenged Descartes's idea and wondered how is it possible for the "mind to know anything about a physical world to which it can never have direct access" (p69). The mind's understanding of the world becomes possible according to Descartes (1986) through the impressions that are received through the body (sensory mechanisms).

Clark (2005) asserts that Heidegger's account of the nature of understanding is radically different from that of Descartes. While Descartes supported the idea that understanding involves extracting ourselves from the world, Heidegger opposed this view and argued that on the contrary understanding is only possible because we have our being-in-the-

world. Heidegger (1962) asserts that we do not first perceive something purely present at hand and then interpret it as a house, or whatever rather we encounter things as already interpreted in terms of a web of possibilities which we apprehend the thing as possessing (p190, 150). Therefore, interpretation is never without presuppositions¹¹. Heidegger asserts that ‘in every case this interpretation is grounded in something we have in advance — in a fore-having (*Vorhabe*) which is the totality of cultural practices which constitute the taken-for-granted background which circumscribes our possibilities for understanding and determines possible ways of questioning. We grasp and interpret objects in terms of a fore-having, a ‘fore-sight’ (*Vorsicht*) which implies that our understanding is mediated by the vocabulary or conceptual scheme which we bring to bear on a problem and a ‘pre-grasp’ or ‘fore-conception’ (*Vorgriff*) of the thing¹² which relates to the fact that in each act of understanding the investigator has an expectation of what will be discovered. (Heidegger 1962, p191, p150).

What Heidegger is here calling into question is the Cartesian ideal that has dominated all of modern philosophy, namely, the notion that truly “objective” knowledge must be presuppositionless or “foundational”, grounded upon some rock-solid, “objective” foundation. Thus, as Kearney (2006, p301) comments “Heidegger maintains that the objectivistic ideal of ‘a historiography which would be as independent of the standpoint of the observer as our knowledge of Nature is supposed to be’ is a false ideal, an idol, in fact, of the understanding¹³”.

**Hans-Georg Gadamer:
The Fusion of Horizons¹⁴**

“Human being, Gadamer argues, is a being in language. It is through language that the world is opened up for us. We learn to know the world by learning to master a language”

(Gadamer as cited in SEP 2006b, p6)

Palmer (1969) argues that Gadamer’s work published in 1960 *Truth and Method: Elements of a Philosophical Hermeneutics*¹⁵ has introduced a new phase for

¹¹ Heidegger referred to these as ‘fore-structures’

¹² Also see Appendix A-Figure 3

¹³ Also see Being and Time, p363

¹⁴ Horizontverschmelzung - Also see appendix A-Figure 4

hermeneutical theory. The radical reconception of understanding by Heidegger was “brought to full systematic expression by Gadamer and its implication for the way the aesthetic and historical are conceived came to light” (Palmer 1969, p163). Gadamer moved away from the idea introduced by Dilthey that hermeneutics should be the methodological basis for the Geisteswissenschaften and challenged the status of the method itself (Gadamer 2006). However, Gadamer does not make it his purpose to inform the methodology of the human sciences, or to develop an art or technique for the interpretation of texts because Gadamer is concerned with a more fundamental question: “how is understanding possible, not only in the humanities but in the whole of the human’s experience of the world” (Drapper 1997, p74)

Gadamer developed a dialogical approach, and grounded understanding in the linguistically mediated happening of tradition (SEP 2006a). According to Palmer (1969) “*understanding*” is not conceived by Gadamer as a “subjective process of man over and against an object but the way of being of man himself; hermeneutics is not defined as a general discipline for the humanities but as a philosophical effort to account for understanding as an ontological process in man” (p163). Gadamer’s approach to hermeneutics based on these different interpretations of “understanding” and “ontology” led to the birth of philosophical hermeneutics.

Kearney (2006) asserts that one of the most outstanding features of Gadamer’s philosophical hermeneutics is the emphasis he places on the historicity of human understanding. Gadamer defends himself against the charge of subjectivism as Kearney (2006) comments “by maintaining that interpretation is never — indeed, can never be — the act of an isolated, monadic subject, for the subject’s own self-understanding is inevitably a function of the historical tradition to which he or she belongs”. Actually, Gadamer challenges the foundation of the objectivists’ theory of presuppositionless understanding, which he claims is an existential impossibility, that, as “Heidegger would say, it involves a thoroughgoing misunderstanding of human understanding” (Kearney 2006, p302-303).

¹⁵ *Wahrheit und Methode: Grundzuge einer Philosophischen Hermeneutic*

Gadamer rejects these arguments asserting that the prejudices which a person holds are derived from that person's historical situation; and he argues that far from being the enemy of understanding, prejudice constitutes its necessary precondition (Gadamer 2006). Ricoeur (1998) asserts that for Gadamer "the prejudices of the individual, far more than his judgements, constitute the historical reality of his being" (p68). Gadamer seeks to restore the concept of prejudice from negative connotations which were introduced by Heidegger in *Being and Time*. For Gadamer our prejudices "do not constitute a wilful blindness which prevents us grasping the truth; rather they are the platform from which we launch our very attempt at understanding" (Dermot 2006). Gadamer (2006) proclaims that this is clearly due to the influence of the Latin '*praejudicium*'. There are such things as *prejudges legitimes* (p273). Gadamer rejects "the usual pejorative view of prejudice which he traces to the Enlightenment ideal of a pure reason unencumbered by native prejudice" and asserts that understanding arises only in and through our prejudices (Dermot 2006, p278).

Gadamer asserts that, our prejudices are indivisible from the historicity of our being: from the fact that all of us are historically as well as socially situated (Palmer 1987). Similarly, Dermot (2006) asserts that we "can not extract ourselves from history in our attempts to understand the process of history; history is always already operative in our understanding. The way a tradition operates is summed up by the term "prejudice" (p. 278).

"Long before we understand ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society and state in which we live. Inasmuch as understanding always occurs against the background of our prior involvement, so it always occurs on the basis of our history"
(Gadamer 1975, p276-7)

Understanding, for Gadamer, is thus always a historical, dialectical, linguistic event (Palmer 1969), while hermeneutical "consciousness" is itself that mode of being that is conscious of its own history "being effected" (SEP 2006b, p6). Gadamer argues that the awareness of the historically effected character of understanding is identical with an awareness of the hermeneutical situation which he describes with the phenomenological concept of "horizon" (SEP 2006b, p6). This concept comprises of a range of vision that

includes everything seen from a particular vantage point (Lavery 2003). The horizon of a particular present is made up from the prejudices that we bring with us since they constitute that beyond which it is impossible to see (Gadamer 1975). Gadamer viewed interpretation as a “*fusion of horizons*”, a dialectical interaction between the expectations of the interpreter and the meaning of the text (Taylor 2002a). Gadamer suggested that we develop a fusion of horizons whereby differing viewpoints come to understand one other by melting into each other through developing a common language.

For Gadamer, “the researcher, and the text which is the object of study, exists within horizons whose boundaries are determined by their historical situation. And horizons take on a particular point of view as the beliefs reflect individual differences” (Draper 1997, p76). Understanding is the result of the formation of a comprehensive horizon in which the limited horizons of text and interpreter are fused together into a common view of the subject matter with which both are concerned - the meaning (Linge 1977).

Hermeneutic Phenomenology Ricoeur’s Hermeneutic Approach

“[For hermeneutics] it is ... to seek in the text itself, on the one hand, the internal dynamic that governs the structuring of the work and on the other hand, the power that the work possesses to study itself outside itself and to give birth to a world that would truly be the ‘thing’ referred to by the text”

(Ricoeur 1991a, p17-18)

For Ricoeur, we can no longer define hermeneutics or the theory of interpretation in terms of the search for the psychological intentions of another person which are concealed behind the text, and if we do not want to reduce interpretation to the dismantling of structures, then what remains to be interpreted?’ (Ricoeur 1981, p141). The answer according to Clark (2005) is a Heideggerian one: the interpreter should aim to inhabit and understand the mode of being studied by the text:

“For what must be interpreted in a text is a proposed world which I could inhabit and wherein I could study one of my own most possibilities. This is what I call the world of the text, the world proper to this unique text....Through fiction and through poetry; new possibilities of being-in-the-world are opened up within everyday reality”. (Ricoeur 1981, p142 as cited by Clark 2005)

Ricoeur’s vital contribution to the discipline could perhaps be said to consist in his having drawn from this ontology of understanding methodological conclusions of direct relevance to the practice of the human sciences. In doing so, he has also addressed the key problem in the philosophy of the human sciences that Gadamer’s hermeneutics tends to leave unresolved, namely, the problem of the relation between explanation and understanding (Kearney 2006, p326).

Based on the SEP (2006a) Ricoeur attempted to bridge ontological and critical hermeneutics, which up to his time were considered incompatible. This incompatibility was based mainly on the genuine differences between the two, however Ricoeur proposed “an alternative that aimed at unifying the most convincing aspects of them both” (p9). In his early work *Symbolism of Evil*, Ricoeur saw hermeneutics merely as a method of interpreting symbols. However, he subsequently refined hermeneutics into a theory of interpreting discourse as a whole, including, but not confined to, the symbols which any discourse contained (Ihde 1971). Ricoeur in his works ‘*From text to action-Essays in hermeneutics*’ (1991a) and ‘*Hermeneutics and the human sciences*’ (1995) asserts that the process of interpreting texts does not involve the realisation or understanding the intentions of the narrator, but to understand the meaning of the text itself; that is the directions of the thoughts that are opened up by the text’s elusive meaning. According to Wiklund et al. (2002) what is opened up, or appropriated, is the disclosure of possible ways of being in the world. Understanding of the text means to follow its movement from the manifest description (what the text says) to what it talks about. “When following the text beyond the situation and the intentions of the author, and beyond the reader’s situation, the text discloses possible modes of being in the world that can be appropriated” (Wiklund et al. 2002, p115). Philosophically, the process of appropriation has its foundations in Gadamer’s concept of tradition. Ricoeur (1981) asserts that “the action of tradition and historical investigation are fused by a bond which

no critical consciousness could dissolve without rendering the research itself nonsensical” (p76).

According to Geanellos (2000) it is “through participation in the tradition in which we live we gain a sense of the familiar and of belonging. Tradition is not alien; it is something into which we have grown, something we have appropriated through engaged living” (p114). Ricoeur (1995) as Gadamer also perceives appropriation as to “make one’s own” what was initially “alien” which is the aim of hermeneutics (p185). According to Ricoeur (1995) the process of interpretation comes to a closure when reading releases something like an event, an event of discourse, and an event in the present time. The result of this process provides the interpreter with a new perspective of things which allows him/her to view the world differently. Ricoeur (1991b) in his work “*On interpretation*” explains:

“that the condition for understanding and self-understanding is the linguistically mediated tradition to which we belong, the whole treasury of symbols transmitted by the cultures within which we have come, at one and the same time, into both existence and speech” (p192-3).

Ricoeur asserts that interpretation allows actualisation of the meanings of a text and this occurs through appropriation (1981, p185). ‘By ‘appropriation’, I understand this: the interpretation of a text culminates in the self-interpretation of a subject who thenceforth understands himself better, understands himself differently, or simply begins to understand himself’ (1981, p158). Therefore the understanding of the text allows the interpreter to expand his horizons (i.e. to know his or herself). That according to Geanellos (2000) “presupposes that we can distance our selves from our pre-understanding (distanciation) in order to perceive new meaning (appropriation)” (p117). Distanciation and appropriation stand in a dialectical relation to one another and culminate in understanding (Wiklund et al. 2002; Geanellos 2000).

Ricoeur (1981) has addressed the difference between text and discourse, referring to these differences as distancing. The four principles of distancing are (1) the transcription itself and the meaning of the written word, (2) the relationship between what has been

written and the intent of the person who wrote the text, (3) the meaning of the text beyond its original intent as well as the author's original intent, and (4) the new interpreted meaning of the written word and the audience. As described by Allen and Jensen (1990, p245) the hermeneutical circle of interpretation moves forward and backward, starting at the present. It is never closed or final. Through rigorous interaction and understanding, the phenomenon is uncovered. The interpretive process that underlies meaning arises out of interactions, working outward and back from self to event and event to self. Ricoeur (1976) points out in his work *"Interpretation theory: Discourse and the Surplus of Meaning"* that:

'Distanciation is not a quantitative phenomenon; it is the dynamic counterpart of our need, our interest, and our effort to overcome cultural estrangement. Writing and reading take place in this cultural struggle. Reading is the 'φάρμακο' (pharmako), the remedy, by which the meaning of the text is 'rescued' from the estrangement of distanciation and put in a new proximity, a proximity which suppresses and preserves, the cultural distance and includes the otherness within the ownness. (p43).

Wiklund et al. (2002) comment that by working within the text, distanciation as the dialectic counterpart of appropriation is possible. The nature of the text holds within itself the foundations for distanciation as its characteristics objectify the text in several ways and give it a life of its own: it focuses the 'what' of the text, rather than the empirical context. Ricoeur attempts with the process of distanciation to remove the authorial intent; that is the idea that the meaning of a text resides only with its author. The way in which the text is constructed to create the narrative will explain something about the text's meaning for the reader. The meaning of the text, its sense, becomes more important than its reference, thus distanciation is not a methodological concern, a technique, but rather it "is a constitutive of the phenomenon of the text as written" (Ricoeur 1976, p44). Therefore, the process of distanciation enables the interpreter to approach the text with an open mind and thereby appropriate its sense through the use of the explanations the text provides the reader with. Those explanations are directed towards a structural analysis of the internal relations of the text and to an analysis of deep structures that could be expressed as metaphors.

Ricoeur argued that the attempt to understand the specifically human must, in the final analysis, assume the form of a narrative: “[...] that human phenomena — texts, action — can not properly be understood until the results of the explanatory approach have been integrated into a wider, interpretive understanding” (Ricoeur 1981, p8 as cited by Kearney 2006). The identification by Ricoeur that the narratives comprise the best approach to investigate people’s lived experiences has informed my decision to implement this technique in this study as a means to collect the research data. Ricoeur (1976) acknowledges that the person’s lived experience retrieved through the narratives can not directly become another person’s experience. However, what can be transferred from one person to another is not the experience as experienced, but its meaning. Ricoeur (1976) asserts that “the experience as experienced, as lived, remains private, but its sense, its meaning, becomes public” (p16). The argument made here by Ricoeur describes the essence of this study; that is to make “public” the meaning of the lived experiences of the patients with cancer and of their nurses.

Table 2.1 key philosophers' main ideas and contributions.

Philosophers	Major contributions to the philosophy of hermeneutics	Influences	Main Works	
Schleimacher (1768-1834)	General hermeneutics as the art of understanding. Interpretation takes place along two different axes: grammatical and psychological	Hermeneutic Circle	Friedrich Ast Friedrich Wolf	Has no published work. Series of lectures
Dilthey (1833-1911)	Saw hermeneutics the foundation of the Geisteswissenschaften- that is, all the humanities and social sciences. Lived experience, the manner in which a life is lived historically.	Dilthey describes two contrasting approaches to the acquisition of knowledge as explanation and understanding. Historicity.	St Augustine Schleimacher Kant	Volume I: Introduction to the Human Sciences Volume IV: Hermeneutics and the Study of History
Heidegger (1889-1976)	Brought the ontology of the subject and the "something" which Husserl disclaimed back into the "experience-of something". Experience was already out in the world; Understanding is deeply entrenched in the profound ontological makeup of Da-sein.	Heidegger identified Da-sein, as a thereness of being that is distinguished by the capacity for self reflection concerning its own existence.	St Augustine Kierkegaard Nietzsche, and Meister Eckhart	<i>Sein und Zeit</i> - Being and Time
Gadamer (1900 - 2002)	'Understanding' is not conceived by Gadamer as a 'subjective process of man over and against an object but the way of being of man himself; 'The prejudices of the individual, far more than his judgements, constitute the historical reality of his being'	Hermeneutics is defined as a philosophical effort to account for understanding as an ontological process in man. The fusion of Horizons.	St Augustine Schleimacher Heidegger	Truth and Method: Elements of a Philosophical Hermeneutics
Ricoeur (1913-2005)	He drew from this ontology of understanding methodological conclusions of direct relevance to the practice of the human sciences. Bridged ontology and epistemology. Distanciation and Appropriation.	Addressed the key problem in the philosophy of the human sciences, namely, the problem of the relation between explanation and understanding.	Dilthey Gadamer Heidegger	Philosophy of the Will, The Rule of Metaphor, Hermeneutics and the Human Sciences, Time and Narrative.

Rationale for choosing a particular research method: why Ricoeur?

The research that aims to search for the understanding of phenomena in the world of caring, it is necessary to reflect on ontological and epistemological concerns before choosing a methodological approach. In this process of choosing the most appropriate methodological approach as Wiklund et al. (2002) assert, the researcher needs to wonder not only about the “phenomenon under study, but also about the relationship between explanation and understanding and whether the research method is consistent with the particular view of human nature that nursing imposes” (p114).

The person is viewed by nursing as one who is interacting with the environment, interpreting impressions and ascribing personal meaning to his/her experiences (Wiklund et al. 2002). The researcher behaves in a similar way and to claim that the nursing is an objective science with one universal truth as Ricoeur asserts (Simms 2004) is foreign to the methodological approach of this study. Here lies perhaps the most radical move, in the development of Ricoeur’s theory, that of objectifying the text which allowed researchers to move beyond the notion that only one understanding is meaningful or correct; that of the research informant (Geanellos 2000). Therefore, this implies that the researcher has to take a stance not only on the question of what knowledge is, but also on the appropriate way to attain that knowledge within the context of research.

The methodological and philosophical views of hermeneutics provide according to Finch (2004) a “new direction for study not only in philosophy but also across many disciplines, including nursing” (p253). Recognising the importance of hermeneutics, the essence of beliefs, values and commitments can become known and clarified. This philosophical stance provides the explanations or perceptions of that which supports an individual’s beliefs and provides the explanation of meaning. Finch (2004) asserts that “Each person brings to the hermeneutical moment a storehouse of pre-understanding derived from human experiences [...] which provides the ‘know-how’ to deal with life’s everyday events” (p253).

I propose a hermeneutic phenomenology approach, inspired by the interpretation theory of Ricoeur (1995) but modified to fit the ontological and epistemological thinking of nursing. My decision was mainly based on four fundamental aspects. Firstly, Ricoeur's theory of interpretation, avoids the Cartesian subject/object split, thereby making it useful for the researcher seeking to explicate intersubjective knowledge. This aligns with my aim to seek to explore the issue of quality holistically, focusing both on the experiences related to the body and mind of the informants. Cartesian thought clearly divided mind and matter, observer and observed, subject and object (Drapper 1997). Descartes as cited by Goldberg (2002, p447) argued "there is a great difference between mind and body, in as much as body is by nature always divisible, and the mind is entirely indivisible.". This was appropriate with my identity as a researcher that belongs to the holistic nursing approach which aims to overcome this Cartesian mental-physical split (Burnard 1990).

Secondly, Ricoeur asserts that "interpretation is the hinge between language and lived experience" (Ricoeur 1976, p66). This is especially so with research narratives and focus groups where lived experience is expressed through language then transcribed into a text and interpreted.

Thirdly, this approach takes into consideration the values, beliefs, and culture (i.e. *historicity* as Ricoeur calls it) of the Cyprus context which are essential elements that need to be explored during the data collection and interpretation processes. Culture and its important influence on the interpretation of text might create a conflict of interpretations and therefore the selected approach needed to be able to address this potential problem. Hermeneutics explore the conflict of interpretations, because the possibility of "very different, even opposing methods" of understanding is a fundamental aspect of our experience as interpreting beings (Ihde 2004, pxiv-xv).

Finally, Ricoeur rejected the idea of bracketing allowing the researcher to adopt a more active role in the interpretation process bringing into the study his/her experiences. Therefore, rather than suspending my preconceptions in this study, I was an active informant in the interpretive process and not a mere passive recipient of knowledge. I re-

immersed myself into the informant's world by reflecting on my own past and professional experiences with patients with cancer. It was deemed impossible and less fruitful to the results of the study to position myself outside of the problem under study.

The analyses of this study's narratives about being treated or providing care for cancer, focus on the meaning of lived experience, i.e. that each narrative contributes one person's perspective of the phenomenon. Therefore, according to Soderberg et al. (1999) the focus of analyses moves from the psychological understanding of the narrators (the utterer's meaning), to the meaning of their lived experience expressed in the text (the meaning of the utterance).

Every decision taken was a reasoned one, reflected the theoretical framework of the methodology employed and be made explicit to others (Koch 1999). All research methodologies hold ideas about the nature of truth and reality, based on alternative epistemologies and ontologies. Researchers must be conversant with these and apply their interpretation of the theoretical framework to the research methods adopted (Whitehead 2004).

The value of hermeneutic phenomenology is embedded in the subjective and often emotional nature of the issue under study. This paradigm, with its emphasis on description, understanding and interpretation, seemed appropriate for my study which aims to investigate the quality of nursing care from the viewpoints of patients with cancer, their advocates and that of the cancer care nurses themselves. Hermeneutics carry the ability to describe the human experience as it is lived and explores the full nature of the phenomenon (Cirgin-Ellett and Beausang 2002). It is through hermeneutical inquiry according to Van De Zalm and Bergum (2000) that practising nurses have the opportunity to find meaning in and understanding everyday situations with patients, to discuss and communicate their understanding with others, and as a result, to change their actions or the actions of others in subsequent situations on the basis of that understanding.

Reflecting on the research questions, the aims and objectives, the desired data, the literature review and the methods of research as a whole, hermeneutic phenomenology integrates all the necessary elements for conducting a successful study. This approach was considered to offer a deeper, more interpretive understanding of human experience and appropriate to explore the experience of the informant with the intent not solely to describe their experience, but to actually interpret it. It is believed that interpretation is required in order to understand human action (Addison 1992).

Consideration of other philosophical and methodological approaches

In the process of choosing the best methodological approach to investigate the research topic, the method of grounded theory was also considered. Grounded theory is a combination of research methodology and method, introduced by Glaser and Strauss (1967), and further developed by each independently (Glaser 1992; Strauss and Corbin 1998). However, some aspects of this method make grounded theory less suitable as the principal approach for my study. Despite the fact that grounded theory has a well-documented process of analysis based on the categorisation of data, and identification of the properties of categories and links between them, this analytical work needs to begin early in the data collection process, so that the developing theory can guide further data collection by both theoretical sampling and theoretical questions in interviews.

With the long overdue opportunity to conduct basic inductive work in the field of patients' with cancer experiences of nursing care, it was useful to remain at this inductive level sufficiently long for much more information on patients' lived experiences to emerge. Grounded theory's emphasis on early coding, linking and theoretical development could have caused the potential of the open approach of this study to be missed, by developing too narrow a focus too early on.

Researcher's Lived Experience

As a nurse with experience in cancer care departments, I have brought to this study certain lived experiences. These experiences are associated with the quality of the nursing care delivered to patients with cancer and the way that nurses cope with the

process of delivering such care. The critical review of hermeneutics revealed that the philosophers in this tradition have acknowledged the importance of the researchers' lived experiences and that these should not be excluded from the research process. Therefore, as a hermeneutic phenomenologist researcher I could not place myself outside of the problem. Heidegger (1927/1962) has identified that it is the researcher's preconceptions that guides interpretation. Ricoeur (1974) also asserts that "interpretation is caught inside the circle formed by the conjunction of interpretation and the interpreter" (p23). Belonging to the informants' world as an "emic"¹⁶ researcher was advantageous and allowed a more complete understanding of the issues under study (Cutcliffe and McKenna 1999). The main goal was to develop an understanding of a complex phenomenon as experienced by its informants. I therefore had to strive to view the phenomenon as the informants viewed it. Hermeneutic phenomenologist researchers are very much like actors wanting to experience their area of study from the inside (Gummesson 1991). Hermeneutical meaning should therefore emerge as a result of co-creation between the researcher and the researched (Wimpenny and Gass 2000).

Therefore, hermeneutic phenomenologists often use themselves as the data gathering instrument (Dempsey and Dempsey 2000). Some informants in the study were willing to share their experiences with me, because they acknowledged that I had been through the same situation, this gave me access to privileged information (Wibberley and Kenny 1994). As a result of this, informants were much more open in their responses and I believe that being accepted as a peer by them was important in eliciting the information for this study. The trust invested in me by the informants allowed a deeper and truer exploration of the experiences of being cared for and providing care for cancer. Patients valued my nursing background and the fact that at the actual time of the research I was not working at the cancer care departments that participated in the study and thus they felt free to express their experiences.

¹⁶ The emic perspective, a term used by ethnographers, refers to the way members of a culture themselves view their world

Conclusion

This chapter has critically described important features of hermeneutics and given a critical overview of the historical development of the discipline. As the thesis develops, it will be seen that hermeneutics offers a critical perspective on the literature of the quality of nursing care; justifies the methodological decisions that were taken during the empirical phase of the study; and informs the development of the findings. Moving to the next chapter, the issue of quality in the specific context of the Cyprus HCS is explored.

CHAPTER 3

HEALTH CARE AND QUALITY: LITERATURE REVIEW AND THE RELEVANCE TO THE QUALITY OF THE NURSING CARE FOR THE PATIENTS WITH CANCER IN CYPRUS

Introduction

The issue of quality in the Cyprus HCS has not been, until recently, taken into serious consideration by the MoH. However, certain circumstances such as the recent accession of Cyprus in the EU, and the introduction of the NHIS have changed this.

The NHIS was launched in May 2001 by an Act of Parliament with the approval of the relevant laws that regulate its implementation and operation. Two years later, the structural arrangements of the NHIS were approved by the MoH. New criteria for the provision and access to the health care services were introduced based on peoples' income with special criteria applying for specific groups¹⁷.

Since the central theme for this study is quality, the focus of this chapter will be the exploration of this issue in the NHIS and some correlations with the UK National Health Service (UK NHS) will be made. The rationale for making such correlations is for two reasons. Firstly, the structures of the HCS in Cyprus were introduced by the British in the late 1940s about the same time that the UK NHS was launched and therefore shared many similarities. Secondly, the UK NHS has undergone major development since its inception, something that the NHIS has failed to do. Many of the changes that have been or will be introduced to Cyprus HCS are similar to the UK example. Nurses, policy makers and nursing directors in Cyprus can learn from the UK example which might help them to structure and introduce the NHIS in a more efficient and successful way.

In this chapter the discussion will be focused on the following:

- i) The Cyprus HCS is described with emphasis on how private and public hospitals operate. The problem of cancer in EU and Cyprus is presented through statistics.

¹⁷ i.e. elderly, public workers, health care workers

ii) The issue of quality is discussed. The relevant literature is reviewed in relation to the definitions of quality nursing care.

iii) The main processes and strategies with which quality will be assured in the NHIS are critically reviewed.

iv) Attaining quality of care in the NHIS and the challenge for nursing is discussed.

Cyprus healthcare context

Cyprus has a mixed HCS, where the public maintains a high level of awareness about choice. Those who choose to pay privately for their treatment are becoming more aware of the value and quality of service they receive for their money. However, when it comes to the sophisticated care required by patients with cancer the majority of the people in Cyprus will at some point use the services provided by the public sector for a variety of reasons, the main ones being the high cost of the private services and the limited services and expertise available within the private sector. One of the most recent effects of the limited private sector was the shift of qualified nurses from the private to the public sector. This created staff shortage and forced the major private provider of cancer services to suspend the operation of one cancer care department. This nursing shortage combined with severe economic constraints of funding available for health care has prompted concern in the Cypriot nursing community regarding patient safety and the quality of care provided to patients (Mpakatzounis 2005; Athanasiades 2005). This is hardly a local phenomenon and the position expressed by the ICN (International Council of Nurses) strengthens this view that “we are immersed in a global nursing workforce crisis – one marked by a critical shortage of nurses” (ICN 2007, p1).

Public hospitals in Cyprus present major differences in relation to the private¹⁸. Public hospitals are responsible for providing primary¹⁹, secondary and tertiary care, whereas the private ones are confined to providing second level care, and in some cases, types of

¹⁸ See appendix B-Diagram 2 and 3

¹⁹ Primary care - The provision of such care by the district hospital is done through out-patient clinics

preventive care (i.e. diagnostic medicine). The public hospitals are struggling to meet the challenge of increasing demand for health care without an increase of resources, an issue further analysed later in the study. As a consequence problems occur in the way the hospitals are organised and managed. The public healthcare staffs' "lifetime contracts" with the government limits any new employment and where these occur they are driven by political or social motives rather than population health needs (Polyneikis and Kalos 1992). The current system of employing government employees prevents swift changes to be made in order to respond to the fast changing health needs of the public whereas in the private hospitals staff can be employed on a temporary basis or be given short term contracts. Staff in the private hospitals can be at any given time decreased or increased to respond to the demand and the financial profit of the organisation (Polyneikis 2007).

According to the CSS (2005), 2500 nurses are employed in the public sector and 750 in the private sector. Based on a population of 747,000²⁰ this means that there are 2.2 nurses per 1000 inhabitants. In "Northern Cyprus" the medical technology and specialist physicians are scarce, a situation that each year forces thousands of Turkish-Cypriots to seek help either in Turkey, or the southern parts of Cyprus. Since April, 2003, when crossings along the so-called Green Line dividing the northern and southern parts of the island were partially relaxed, more and more Turkish-Cypriots have been seeking care in the south. According to statistics given to "The Lancet" by the health ministry's permanent secretary Sotiris Soteriou between April, 2003, and December, 2004, 24,420 Turkish-Cypriots were treated in government medical institutions. This includes the Bank of Cyprus Oncology Centre and the Institute of Neurology and Genetics providing services financed by the government (Antoniadou 2005). Therefore, if these Turkish-Cypriots that visit the hospitals of the Republic of Cyprus are to be included in the total estimated patient population that uses the HCS then there is a considerable increase in the load on the health services in Cyprus. Despite the fact that Turkish-Cypriots patients visit the Republic for various treatments there is no evidence of a similar move of patients from the south to the north. This phenomenon creates additional burden on the

²⁰ Greek-Cypriots only

health services which are already struggling to meet the increased demand for health care from the Greek-Cypriots²¹.

The private hospitals' operation is contingent on market incentives. Because private hospitals are not subsidised and depend on income from clients, it can be argued that they are more inclined than public hospitals to provide quality services and to be concerned about client satisfaction. By doing so, they are not only able to build satisfied and loyal clients who revisit the same facility for future needs, but the clients also serve as a source of referrals who recommend the private establishments to friends and family, thereby sustaining the long-term viability of private hospitals. However, the ability of these market mechanisms to deliver more effective and efficient services and therefore higher quality has received criticism by many commentators (Nichols et al. 2004; Hurley et al. 2004; Strunk et al. 2002).

In public hospitals, there are little or no market incentives in operation. Tax subsidies assure these organisations of their survival (Polyneikis 2006). The Cyprus media regularly provide evidence of their lack of responsiveness, dedication, or quality assurance (Kasinidou 2005; Karakatsani 2004a). This suggests that their service quality will be rated lower than private hospitals though factors such as the public hospitals dealing with many more difficult cases than the private sector, who can choose what it provides, must be taken into account. Account must also be taken of the nature of public bureaucracies and the lack of incentives they provide for efficient resource use. Decision-making in Cyprus is usually highly centralised and planning and management structures weak (Polyneikis 2003; Hsiao and Jakab 2003; Nuffield Institute for Health 1994, 1998). Government regulations impede action to improve efficiency (e.g. adjust staff numbers to local workloads), and the MoH, even if it wishes to, has very limited ability to introduce greater flexibility on its own authority. There are many reasons for this. Firstly, the Union for the government employees in Cyprus is very powerful and often uses strikes and other dynamic measures to pressure the government not to adopt many of the changes suggested by the MoH if they might feel that their rights are

²¹ See appendix C-Table 2a, Table 2b

threaten in any way. Secondly, any decisions made by the MoH in relation to the increase of the staff need to be made in collaboration with the Ministry of Finance. Therefore, in many cases their decisions are limited by the government budget. Finally, the health management cadre is dominated by medically-trained staff, which has little management training and is supported by relatively poorly educated administrators (Polyneikis 2003).

One mechanism to contain health care costs, as in other countries, is to reduce the number of registered nurses and replace them with unlicensed nurses or other licensed personnel (Kasinidou 2004). In Cyprus, during the last year (2006), the private clinics owners attempted to equate assistant nurses (i.e. auxillary) with qualified nurses as a response to budget cuts. This attempt triggered a reaction by qualified nurses, professional associations and the public, who claimed this would endanger their health and that such changes could adversely impact the quality of care received by the Cypriots (CYNMA-Cyprus Nurses and Midwives Association 2006).

Another side effect of the cost constraints that had an impact on the quality of health care was the decision of the government to close down one of the cancer care departments operating at the NGH (Nicosia General Hospital) (Karakatsani 2004a). Consequently, the ability of the hospital to treat patients was decreased by 35% causing reactions such as protests and strikes by the patients, their relatives and the public, forcing the patients to seek cancer services elsewhere. The situation was worsened by the fact that there was not (and still there is not) a strategic plan on which cancer care services can be organised so that the problem of cancer can be tackled and patients offered the best possible medical and nursing care (MoH 2005). The decisions, planning and actions that followed the closure of the cancer care department at NGH could only be described at the moment, as a desperate measure to meet desperate situations. This decision was part of a plan for decentralising cancer services and transferring some major cancer services to LGH (Limassol General Hospital). However, this was an impulse measure without the necessary planning from the MoH. The fact that the planning took place behind closed doors and without the cancer care organisations,

cancer care associations, patients and cancer care professionals' opinions being heard by the MoH created disbelief among the patients, their families and the people of Cyprus (Alexandrinou 2005). The restructuring of the cancer care services generated an unstable atmosphere between the government, the patients, their families and the public and sparked some intense reactions. These can be seen in some of the headlines that flooded the national media. A characteristic example of these reactions follows "[...] Patients with cancer have taken the law into their own hands [...] Yesterday they seized the closed cancer care department at NGH protesting against the decision of the ministry to be treated in other departments of the hospital [...]" (Karakatsani 2004b), "[...] Patients with cancer hunger strike outside the presidential residence continues for 38 days now, without any signs on behalf of the MoH for reaching a solution to the problem of decentralising cancer care services [...]" (Karakatsani 2004c).

Despite their differences, the public and private health care systems share an important organisational aspect related to the delivery of the care. The care is delivered based on the traditional biomedical model but with some recent attempts to move towards a more bio-psycho-social care, a model first introduced by George Engel (1913-1999) (Borrell-Carrió et al. 2004). The traditional biomedical model has exemplified the delivery of health care in Cyprus, and it is characterised by an objective approach to patients, which considers both their bodies and their diseases as objects. However, with the introduction of the NHIS the bio-psycho-social model will be introduced to health care delivery, a model with clear applications for the nursing care as well as the medical practice (MoH 2003). The bio-psycho-social model unlike the biomedical model is characterised by an approach that considers patients holistically and their disease as a complex event consisting in an alteration of the system at several different but integrated levels, biological, psychological and social (Engel 1980).

European and Cyprus statistics on cancer

The papers "Health related statistics" (2002) and "Sigma" (2005) launched by the European Commission offer a complete picture of the problem of cancer in Europe. Excluding non-melanocytic skin cancers, there were 1.594379 new cancer cases and

927.740 deaths due to cancer in the EU²² in 1997. In the EU with a membership of 25 states there were 2.886800 incident cases of cancer in 2004 and 1.711 000 cancer deaths (Boyle and Ferlay 2005). Cancer occurs more commonly in males than females and currently accounts for 28.5 % of male deaths and 22.0 % of female deaths²³ (AECL-Association of European Cancer Leagues 2005). The age-standardised European population incidence rate in the EU in 1997 for all cancers was 419.0 new cases per 100 000 for men and 296.8 per 100 000 for women, resulting in an age-adjusted sex ratio of 1.4 (an incidence of 345.1 per 100 000 for the two sexes together). Men have a higher incidence rate for every cancer site, except breast (extremely rare in men) and thyroid gland. The highest incidence for men was found in the Netherlands (465.6) and France (460.7) and the lowest in Greece (338.1) and Sweden (356.9). For women, the highest incidence occurred in Denmark (396.5) and the UK (366.8) and the lowest in Greece (231.4) and Spain (242.1). At the incidence rates prevailing in 1997, it would be expected that one in three men and one in four women would be directly affected by cancer in the first 75 years of life. According to the AECL (2005) cancer is the second main cause of death in Europe, after circulatory diseases.

As in the case of the EU, for Cyprus cancer remains a major cause of morbidity and has been identified as a major public health issue affecting one in four of the population (CSS 2003a). Based on the “2003 Yearly Report²⁴” launched by the Cyprus MoH, cancer is considered as one of the “new epidemics” of our time along with heart diseases. Cancer claims 10% of the total number of deaths, and is considered one of the biggest killers. The profile and management of cancer has changed dramatically in recent years, including shorter inpatients stays, an increasing older cancer population and significant improvements in treatments outcomes and effectiveness. However, despite the recent reforms to service delivery little attention has been given to the quality of the health services provided (Polyneikis 2006).

²² 15 member states

²³ See appendix A-Chart 1

²⁴ Last year for which complete statistics exist

In 2004 the papers “Health Survey” and “Health and Hospital Statistics” were released by the CSS in relation to the health status of the Cypriots. Unfortunately, these statistical reports do not provide information on the private sector where cancer care is also provided (CSS 2003b). This has proven to be a persistent problem not only for Cyprus but for the EU as well (European Commission 2005). Based on the “Health Survey” paper the total number of men with the existence or history of malignant tumour was 2.854 while for women it was 6.258²⁵. Men aged 70-74 had the highest possibility of developing cancer followed by the 65-69 and the 35-39 age groups²⁶. Women differ, in that they have more possibilities of developing cancer if they are aged 55-59 while they have fewer chances if they belong to the 50-54 and 75-79 age groups²⁷. According to the paper “Health and Hospital Statistics”, 416 patients with cancer died (256men-160women). Comparing, the statistics from previous years (1997-1999) the pattern has not change. Male patients tended to have lower survival rates than women²⁸. In 2003, a total number of 3.574 of which 1.889 men and 1.685 women with neoplasm were treated in all the General Hospitals’ cancer care departments with the average length of stay being 7.0 and 7.6 days accordingly²⁹.

For the same year the numbers for the rural hospitals were significantly lower. A number of 44 men and 14 women were treated in these hospitals with their length of stay to be estimated at 4.6 and 6.4 accordingly³⁰. This is not surprising since in Cyprus, health care services are highly centralised. The commonest form of cancer in men was prostate cancer, with an estimated total of 36 deaths. The second most common cause of death was lung cancer followed by colorectal cancer, with the deaths estimated at 33 and 32 accordingly. Men have a higher incidence rate for every cancer site, except breast and malignant neoplasm of meninges, brain and other part of central nervous system³¹. The

²⁵ See appendix C-Table 3 and 4

²⁶ See appendix C-Table 3

²⁷ See appendix C-Table 4

²⁸ See appendix C-Table 5

²⁹ See appendix C-Table 6

³⁰ See appendix C-Table 7

³¹ See appendix C-Table 5

commonest cause of death for women was breast cancer (26 deaths) followed by colorectal cancer (18 deaths) and brain cancer (15 deaths)³².

What is quality in nursing care?

It is difficult to determine the origins of the term quality however, according to Lin and Schneider (1992) concerns about quality have been a feature of industrial technology for a number of years, becoming an everyday term used for such diverse resources as electrical goods, food and transport. Quality has become the hallmark of modern management and is firmly entrenched on the political agenda where quality is used to ensure public accountability, patient satisfaction, appropriate care and value for money in public sector services. It is perhaps difficult to conceive that quality of health care, and more importantly, nursing care can be viewed in the same way as the quality of food or transport, but given the Oxford English Dictionary (OUP 2002) definition of quality as a “degree of excellence”, it can be argued that quality in nursing revolves around the excellence of nursing care.

Hogston (1995) asserts that nursing has struggled since the 1960’s to capture its meaning and emphasised that it has many constituents which include ability, performance, competence, clinical judgment, knowledge, skills and accountable behaviour. The literature points to a large vocabulary under which the umbrella term of quality is used. Quality has been termed as a “nebulous concept” (Van Maanen 1981) because it lacks constant definition in the literature (Redfern and Norman 1990) and because terms such as quality assurance, standards of care and quality control are often used interchangeably (Nielsen 1992).

Florence Nightingale (1820-1910) was the first to recognise the concept of quality for nursing practice. Nightingale succeeded in bringing about improvements in both the living standards and health services for soldiers by documenting mortality statistics of soldiers and bringing these to the attention of the government (Barnham 2003; Taylor et

³² See appendix C-Table 5

al. 1991). Her standards to assess the care of the soldiers and the need for reform have been established as the first documented efforts of quality improvement work, and since then, assurance of quality nursing care has remained a priority for nurses throughout the world (O'Connor and Rogertson 2003). Subsequently, according to Kavari (2006, p11) "nursing has developed into a profession with an emerging unique body of knowledge and this has resulted in a growing interest in the improvement of quality nursing care".

Whilst Nightingale was working in nursing and health care quality, another important figure appeared; that of the physician Earnest Codman (1869-1940). Medical professionals consider Codman, a surgeon at Massachusetts General Hospital at the beginning of the century, to be the father of the search for quality health care (Al-Assaf and Schmele 1993). His commitment to better processes and practices led Codman to introduce the compilation and analysis of surgical outcomes. Codman had planted a seed that helped initiate the American College of Surgeons. Researchers have turned to his writings for philosophical guidance since clinical outcomes research has become a key topic today (Mulley 1989; Berwick 1989).

Another pioneer on quality issues was Donabedian (1988; 1988a; 1980) who has suggested that quality is composed of three distinct but interlinked components; structure, process and outcome. Structure is concerned with the health care setting, process with what happens or how the care is delivered and outcome is demonstrated by patient satisfaction and information. Donabedian's framework has been adopted in many health care settings as a method for setting standards of nursing care. The reason why this model has dominated in health care lays in the fact that it addresses quantified aspects of care.

The various interpretations of what constitutes quality reveal that these reflect the health care climate of the time. Lang (1976) defined quality in nursing care as a "process" which seeks to attain the highest degree of excellence in the delivery of patient care. Harvey (1996) attempted to classify the development of quality in health care by drawing on experiences within the industrial quality movement. He proposed that quality nursing care as well as medical needs to be defined in the context of three

dimensions: (i) quality at an individual level, (ii) quality as inspection and (iii) quality as improvement. Based on Harvey's approach to quality, nursing has been more familiar with inspection-based approaches, although latterly, the focus has been moving towards improvement.

Quality in nursing care according to Gunther and Alligood (2002, p335) refers to the scope of nursing – its view of reality, its place in and relationship with society, and its unique knowledge base. To provide high quality nursing care requires mastering of the knowledge of basic life sciences. Building on this foundation, the nurse adds specialised knowledge from other health care disciplines pertinent to the patient population. Additionally, quality nursing care involves an understanding and utilisation of principles from the social sciences (Gunther and Alligood 2002).

These definitions illustrate that nursing despite a perceived philosophy of holism and humanism relies heavily on Donabedian's industrially derived structure-process-outcome model³³. Nurse theorists have challenged the model and suggested modifications, which implies that the model was inadequate for the nursing paradigm. However, surprisingly it remained the base of these models. The Nursing role effectiveness model³⁴ developed by Irvine et al. (1998) included Donabedian's work and emphasised the individual nurse, the healthcare organisation and patient-centred outcomes (Korniewicz and Duffy 2003, p6). Similarly, the Quality-caring model³⁵ developed by Duffy and Hoskins (2003) also incorporated aspects of Donabedian, Irvine, and Watson and Foster's (2003) work.

From the definitions that have been retrieved from the literature the one proposed by Redfern and Norman (1990) according to whom quality is defined as totality of features and characteristics of a product or a service which bear on its ability to satisfy a given need, is notable. The reason why, lies in the following comment by Redfern and Norman (1990, p1262) that the quality of nursing care must also incorporate considerations of

³³ See appendix C-Table 1

³⁴ See appendix A-Figure 1

³⁵ See appendix A-Figure 2

equity (care being fairly distributed), accessibility (being available and not unduly restricted by time or distance), acceptability (provided in such a way as to satisfy reasonable expectations of patients, providers and the public), efficiency (resources not being wasted on one person to the detriment of another), effectiveness (achieving the intended benefit for the individual and the community) and, perhaps most important, appropriateness (meeting the actual needs of individuals, families and communities).

These considerations highlight the point that quality nursing care is influenced predominantly by social values and if this is further expanded it also touches on the aspect of culture. Ultimately, it is a social and cultural construct negotiated between providers of the service, recipients and those who control the resources. I have recognised the influential nature of culture for quality and therefore I have explored the ethnohistory of the people of Cyprus in order to identify in what way such influences materialise.

What then is meant by the quality of nursing care? The meaning of the concept is multi-layered and complex. As Normand et al. (2002, p414) comment,

“Attempting to define the nature of nursing quality, to value fully the need to meet the more holistic needs of patients and the community in terms of the external body, the psychosocial aspects of care and the social world, goes against the grain of the current orthodoxy”

Further to this opinion Gunther and Alligood (2002) added that nurse scholars often overlook or fail to recognise the significance of Chance’s (1982, p63) observation: “Professional accountability or quality of care is directly linked to the use of nursing knowledge”. I share these views of Gunther and Alligood (2002) and Chance (1982), as well as the views of other scholars and researchers, who agree that quality comprises a critical element of health and nursing that needs to find its own path so that it is not left behind by developments in the health area.

The majority of studies had primarily examined the meaning of quality nursing care from the nurse’s perspective (Hogston 1995; Janhonen 1993). However, it was studies

such as the one by Von Essen and Sjoden (1991) which called for studies incorporating the views of the patients in relation to quality. They investigated the views of patients and nurses in Sweden and who concluded that nurses viewed quality differently than the patients did. Therefore, the notion of quality might incorporate contrasting, even paradoxical ideas: it can be seen as a notion of achieving standards and norms on the one hand, and on the other, as enhancing variability and adaptability to changing environments (Normand et al. 2002). Moreover, the development of an internal market means that purchasers of health care look to the providers for evidence of their quality mechanisms. Purchasers ask questions about the standard and quality of nursing care and the indicators that will be used within the contracts to measure quality. Furthermore, patients expect value for their money and count on the existence of services when needed. More and more patients are demanding to be informed partners in decisions regarding their health (Charles et al. 1999), and their concerns are now directed at the whole spectrum of their care whilst in a health care institution (Ruland and Bakken 2001).

Moreover, it was events such as the British government's criticism in the early 1980s that insufficient note was taken of patients' views and experiences of health services that led research for quality to gain a new perspective, that of the patient, as Williams (1998) comments. Such events influenced the health service policy for quality of care in a way so that quality is no longer only assessed by health care providers but also users. Patient views on what is important in connection with the care they receive have increasingly come to be used as an indicator of this quality (Taylor et al. 1991; Davies and Ware 1988). The proliferation in patient satisfaction surveys also bears witness to this policy however, not without criticism as to the value of such surveys (Johansson et al. 2002; Gilleard and Reed 1998; Smith 1992). In the context of health care, quality is more than the consequence of patient satisfaction since the expectations of patients may be low and their knowledge limited. However, this approach reinforces Donabedian's opinion (1980) who considered that patient satisfaction is a judgement of the quality of care and not a part of the definition of quality. The value of satisfaction surveys was further challenged by McMillan et al. (1986) who claimed that these surveys are biased towards

the positive, as most patients are hesitant to openly criticise the care they receive although they might make negative remarks during conversations with friends. Studies focusing on the patient and their family's perceptions also followed (Oermann et al. 2000; Irurita 1999) and a few have compared the perceptions of nurses and patients (Kunaviktikul et al. 2001; Haggman-Laitila and Astedt-Kurki 1994). Quality nursing care as proposed by Kunaviktikul et al. (2001, p782) took into consideration the perspectives of nurse administrators, staff nurses and patients and found that "quality nursing care is nursing's response to the physical, psychological, emotional, social and spiritual needs of the patients provided in a caring manner, so that the patients are cured, healthy, to live normal lives". The presence or absence of needs is seen as a central determinant of quality nursing care for both nurses and patients and it is assessed in terms of the degree to which these needs are met.

The American Nurses Association (ANA) (1996) emphasises patient needs satisfaction and its interrelationship with quality nursing care. Patient opinion of the care received from nursing staff during the hospital stay is determined by scaled responses to a uniform series of questions designed to elicit patient views regarding key elements of nursing care services. Quality of nursing care may be influenced by the nurse-patient relationship, the patient's active participation in decisions about their care and public awareness of nursing care (ANA 1996). Finally, other factors that can link quality of nursing care may be associated with the nurse's role, such as patient advocate, mediator, guide, or coordinator of care (Mrayyan 2006; Santy 2001).

In order to reach to a collectively acceptable definition of nursing quality is a complex task. Quality and standards are closely related notions and they are distinguishable in that quality is something towards which we constantly strive and which we may never achieve, whereas standards are attainable, if set at a realistic level. Therefore, the notion of quality may include different levels; it is often subjectively measured (process) and contextually related (outcome). Sale (1996) defined standard as "an optimum level of care against which performance is compared" (p40). The ANA (1998) defined standards as "authoritative statements by which the nursing profession describes the

responsibilities for which practitioners are accountable” (p5). Therefore, it could be argued that standards are vehicles to achieving and objectively measuring quality.

In the United States the ANA is responsible for defining the scope and standards of generic nursing practice. In the light of the escalating costs for health care, ANA revised the standards of clinical nursing practice, broadening professional role expectations in an attempt to increase the quality of the nursing care provided and to minimise as a result the necessary expenses (ANA 2003). The standards apply to nurses in clinical practice across health settings and may be used in quality assurance programs as a means of evaluating and improving care. The standards are also a resource for assessment tools and plans of care, and may be used in the peer review and performance appraisal processes (ANA 2003).

The EFN (European Federation of Nurses Associations) identified the need to include nursing quality indicators in national health reports and to have a clear view on the nurse/patient ratio in order to evaluate the outcome and share information on salaries and remuneration (EFN 2005). The EFN states it is important to monitor and document benefits and outcomes including the cost-effectiveness of nursing interventions. According to the 2005 EFN position statement, an increasing number of people will need help at the end of life, in a social context of changing family structure and wider migration, employment and ageing of potential caregivers. It becomes necessary to address the impact on care of changes in family structures. For patients, quality means independence, empowerment and end of life choices whilst for nurses, quality issues are informal and formal recognition, support, training, retention and attractive career. And for institutions, quality is determined by incentives, integrated care and measurable outcomes (EFN 2005).

According to the ICN, the quest for quality and cost-effective health care has brought evidence-based practice and nursing research into the forefront (ICN 2006). Nursing research is a systematic enquiry that seeks to add new nursing knowledge to benefit patients, families and communities. It encompasses all aspects of health that are of interest to nursing, including promotion of health, prevention of illness, care of people of

all ages during illness and recovery or towards a peaceful and dignified death (ICN 1998). The knowledge generated through nursing research is used to develop evidence-based practice, improve quality nursing care and to maximise health outcomes and cost-effectiveness of nursing interventions.

The national and international focus on quality

Although the pursuit of quality improvement and quality assurance has been a key feature of both service and manufacturing industries since the 1970s, the introduction of a focus on quality into the National Health Systems in developed countries was, in comparison, relatively late, and in response to fiscal pressures (Murray et al. 2003).

According to Aiken (1988) and more recently Mays et al. (2004) cost-containment strategies have focused on (1) increasing productivity and efficiency, (2) limiting the growth of wages and prices, and (3) reducing the amount of care provided. The greatest cost savings can be realised by reducing the amount of care provided and therein lays the current dilemma: how to reduce services and maintain quality of care. Without this knowledge, the tendency has been to reduce services across the board, resulting in uncertainty about the quality and distribution of health care services among patients, payers and health care professionals.

However, containing the cost without affecting quality requires information on the effects of health care. This need was the driver in the current emphasis on patient outcomes as measures of quality of care. Hence, the shift in the evaluation of health care services to the focus on effectiveness rather than on quality. Although these terms are similar, they are not identical. Health care professionals have tended to define quality in terms of efficacy – the outcomes that can be achieved when a treatment/care occurs under ideal conditions – that is, provided by the most skilled practitioner in the best possible circumstances (Johnson and McCloskey 1992). Quality then becomes difficult to achieve; better outcomes are potentially possible if one can improve the conditions under which the care is provided. This makes it difficult if not impossible, to define and consequently to measure quality. Effectiveness, on the contrary, indicates the outcomes

or benefits that actually are achieved under ordinary circumstances for typical patients (Lohr 1988).

Similarly the HCS in Cyprus experiences fiscal pressures. Latest statistics show that the total expenditure on health services during 2003 is estimated at C£426.5m of which C£215.4m represent expenditure of the public sector and C£211.1m of the private sector. The share of expenditure on health as a percentage to GDP (Gross Domestic Product) increased from 5.3% in 1998 to 6.3% in 2003³⁶. However, in a study performed by the CSS (2003), Cyprus and Latvia are the two countries with the lowest expenditures in relation to health in the Europe of the 25. According to the same study the countries with the highest health expenditures are France (8.9%), Sweden (8.5%) and Germany (8.1%). The health care industry accounts for about the 16% of the 2004 GDP of the United States having risen from 5% in 1960 (Kaufman and Stein 2006). Similarly in the UK the cost of health has been increasing. The health expenditure for the year 2004-05 according to the DoH climbed in the NHS to £36 billion, 3 billion more than the 2003-04.

As one response to the increasing expenditure on health, the government of the UK introduced the notion of clinical audit. In 1989, the White Paper, *Working for Patients*, saw the first move in the UK to standardise clinical audit as part of professional healthcare. The paper defined medical audit (as it was called then) as “the systematic critical analysis of the quality of medical care including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient”. Medical audit later evolved into clinical audit. The NICE (National Institute for Health and Clinical Excellence) published the paper *Principles for Best Practice in Clinical Audit* (2002, p5), which defines clinical audit as “A quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change”. Clinical audit now comes under the Clinical Governance umbrella and forms part of the system for improving the standard of clinical practice (Jones and Cawthorn 2002).

³⁶ See Appendix C-Table 8

Clinical audit was incorporated within Clinical Governance³⁷ in the 1997 White Paper, “The New NHS, Modern, Dependable”, which brought together disparate service improvement processes and formally established them into a coherent Clinical Governance framework. Clinical Governance is a system through which NHS organisations are accountable for continuously improving the quality of services, and ensures that there are clean lines of accountability within NHS Trusts and that there is a comprehensive programme of quality improvement systems. In the UK, the launch of clinical governance placed quality at the centre of the NHS. Although it was introduced across the NHS, its principles apply equally across the independent sector, as shown by the creation of the Care Standards Act (2000). Clinical governance aims to integrate all the activities that impact on patient care into one strategy. This involves improving the quality of information, promoting collaboration, team working, and partnerships, as well as reducing variations in practice, and implementing evidence-based practice.

Improving the patients’ experience of health care is seen as the central purpose of clinical governance and its importance is highlighted by the documents NHS Cancer Care Plan released by the British government in 2000 and more recently the NHS Cancer Care plan and the new NHS (2002) and Creating a patient-led NHS: Delivering the NHS Improvement Plan (DoH 2005). According to Wensing and Elwyn (2003) it is an ethical and legal rule that patients are informed and involved in their health care, at least to some extent and minimal standards. Patient and public involvement is vital to improving the quality of health services, and opportunities can be provided to make sure that patients are able to contribute to a range of activities – including planning new services, staff training and education, and the development of information. Patients need to be given opportunities in decision-making because they are experts on receiving health care and because they want their preferences to be respected³⁸. As such, they have an influential role to play in the development of health services (Currie et al. 2005). According to Litva et al. (2003) there is difference in the perceptions of professionals and the public regarding how the latter could and should be involved in clinical

³⁷ The Royal College of Nursing (2000) defines clinical governance as “a framework which helps all clinicians including nurses to continuously improve quality and safeguard standards of care”.

³⁸ See appendix A-Figure 5

governance. Patient and public culture will need to meet, to enable successful implementation of the policy of public involvement. Primary care trusts should not develop strategies for public involvement in isolation. They must seek to influence culture shifts. There is a need to reconsider who the “public” is and what constitutes a public viewpoint. Without such an approach, and the resources to support it, effective public involvement in clinical governance is unattainable.

Around the world, countries, health departments, medical and nursing associations have identified the need to focus on quality as a means by which to decrease the financial cost and improve the quality of care provided. Clinical audit, quality standards and patient involvement are only some of the strategies that have been introduced in health care. The fact that in the developed countries such as the US and the UK quality improvement has been adopted as an overarching strategic approach to the problem of cost containment has influenced health service policy in Cyprus. In the next section the development of quality issues in Cyprus health policy is analysed and correlations are been made with the UK NHS.

Health care quality in Cyprus

The experts who developed the NHIS highlighted the lack of quality initiatives during their early deliberations when they pointed out that, whilst the current health system rans on the ability and education of its workers, its structure contained no incentives to improve quality (Pashardes and Pasiourtidou 2006). For health services in Cyprus the focus was on provision rather than receipt of services for many years, and the need to attract, satisfy and retain “users” paradoxically did not rise as an issue. However, as the patient of the health system began to transform into the user of the health services, so the issue of quality of care became more prominent on the managerial and professional agenda. Whilst this does not indicate that those engaged in the delivery of health care services were unaware of quality, it does perhaps signify that there existed a somewhat subjective, unstructured notion of quality which had largely remained unarticulated, and this may go some way to explaining the difficulties that have arisen in relation to determining the nature of health care quality (HIO 2007a). Examining health care

quality within a political framework is an issue which has been at the forefront of policy developments in recent years, and a key aim in the implementation of the NHIS. However it has been highlighted that there has been a significant lack of appreciation for the complex area of quality in the NHIS (Polyneikis 2003).

In terms of the political perspective, health care quality has taken on a very specific meaning, and is largely viewed as “value for money”, and the measurement of health care outcomes. This has resulted in a change in the way quality measurements have been related to efficiency rather than effectiveness (WHO 2000). The introduction of the tables of good hospitals and effective physicians is a function of this change taking place within the NHIS. The MoH plans to publish the first “league tables” for Cyprus allowing health professionals and their patients to scrutinise hospitals’ performance. However, the criticism that followed the introduction of these tables in other countries such as the UK (Brown 2002; Klein 2002) also occurred in Cyprus.

Even though in Cyprus there is a tendency for developing more appropriate measures for health care outcomes which could be used to determine the benefit from health care interventions in terms of health status, there is a lack of consensus over the definition of quality in relation to health care. This lack of consensus resulted in policy makers adopting performance indicators as measures of service quality. In Cyprus the level of activity has been a traditional measure of the NHIS performance, and this level of activity continues to be evaluated in relation to the length of waiting lists, the underlying belief being that any failure in performance would reveal itself in lengthening of the waiting lists. This proved not to be a sensitive measure as waiting lists have continued to increase due to the increased demand for health services from an aging population and, possibly, the large numbers of the Turkish-Cypriots seeking care in the hospitals of the Republic of Cyprus.

Waiting lists have a central place in the experience and perception of health care in the NHIS and UK NHS, although they are also a feature of publicly funded health systems in other countries (Derrett et al. 1999; DeCoster et al. 1999; Bosch 1998). In the UK, this traditional benchmark of performance has been replaced by a focus on the length of

wait, rather than the length of lists (National Audit Office 2001). It is argued by Martin et al. (2003) that it is irrelevant how many people are on the waiting list, what matters is how long those on the list have to wait for their treatment. However, this change is not without its problems, and whilst the data is easily accessible it is neither reliable as a quality measure, nor easy to interpret (Frankel et al. 2000).

A performance measure that has begun to be used in the NHIS and which is also widely used in UK NHS is the user satisfaction survey. Satisfaction and its measurement are important for public policy analysts, healthcare managers, practitioners and users (Crow et al. 2002). Although there appear to be difficulties in defining and measuring “satisfaction”, the concept continues to be widely used. In many instances when investigators claim to be measuring satisfaction, more general evaluations of healthcare services may be taking place (Aspinal et al. 2003; Staniszewska and Ahmed 1999).

Assuring quality in the NHIS

Professional staff fears that the focus on quality in the NHIS would develop into a preoccupation with cost effectiveness at the expense of concern with the quality of care. There was a degree of consensus in the recognition that the extensive adoption of a commercial framework for quality was inappropriate, and that quality within the health care context had to be greater than a consequence of patient satisfaction (CYNMA 2006; CYNMA 2005). These fears raised by nurses in Cyprus echoed a growing body of literature (Jackson et al. 2001; Newsome and Wright 1999; Jackson and Kroenke 1997; Redfern and Norman 1990) that asserts that quality in the context of health care and particularly nursing quality should not be limited to patient satisfaction since the expectations of patients may be low and their knowledge limited. When the nature of the treatment is thought to be highly technical then it is likely that many service users will not hold on to their own expectations as Williams (1994) asserts. This is true of many healthcare scenarios according to Newsome and Wright (1999, p164) “where the technical quality of the service - the actual competence of the provider or effectiveness of the outcome - is not easy to judge. The patient may never know for sure whether the service was performed correctly or even if it was needed in the first place”. Therefore,

when considering the key components of quality previously identified: i. access, ii. equity, iii. acceptability, iv. efficiency, v. effectiveness and vi appropriateness, a number of dilemmas have emerged as the attempts to quantify quality in Cyprus have developed. Not surprisingly, analogous dilemmas occurred earlier in the UK and were acknowledged and discussed by scholars such as Whitehead (1994) and Philips et al. (1994).

i. Access

When considering access to health care services, the change which it is hoped to be achieved is the creation of GP fund holders which can be seen to provide a fast track to both hospital consultations and admission for elective surgery, thus allowing the patients of GP fund holders to enjoy improved access to services not so easily accessible to the patients of GPs who are not fund holders. When appraising access to health care services, there is a need to incorporate not only issues relating to physical access, but also concerns about the range and level of appropriate services, as well as the distribution of such services (Rowell 2004; Avis et al. 1995) . Such information is not consistently collated in Cyprus, as services undergo change and development, and access may vary within the financial year. In addition, responsibilities for access can be seen to be shared between purchasers and providers, and so the information available may be fragmented or incompatible (Illiades 2007). Therefore, it is impossible to comment on the quality of health care in terms of access in its broader sense.

ii. Equity

A number of components within the NHIS, as it is established, that can be seen to relate to equity (Golna et al. 2004) have been identified such as the selection of patients for treatment on the basis of clinical need, dissociated from the ability to pay for health care services, the universal entitlement to health care, the provision of free health care services at the point of delivery and the non-exploitative philosophy which underpins the service.

In the Cyprus media, the health services are experiencing frequent challenges that some of these components are being eroded; however there is a lack of current research evidence to confirm or deny such claims. Therefore, when considering the impact that the NHIS potentially may have on the quality component of equity, there is a significant lack of data, as well as a lack of consensus as to how equity should be determined. A similar difficulty in drawing a widely accepted definition in relation to equity has also occurred in the UK. On this matter Malek et al. (1993) and Whitehead (1992) assert that it is not that easy to ascertain the precise notion of equity adopted by the NHS. This ambiguity creates some problems, because each notion carries a different ideological weight and has different policy implications.

Indeed, it has appeared to be the case that the rather narrow definition of equity which relates to access only, will result in only partial data being available on which to evaluate the effects of the NHIS on equity (Braveman and Gruskin 2003; Chang 2000). There is also a divergence of opinion as to the future effects of the NHIS on equity, and whilst some claim that the NHIS will be associated with greater inequality (Hsiao and Jakab 2003; Agrotou and Kalakouta 2000), others argue that there has always been inequality in the health services, and the NHIS will merely make that inequality more visible (Antoniadou 2005; Gojna et al. 2004).

iii. Acceptability

When considering health care quality in relation to acceptability, again there arises the fundamental difficulty of the separation of the purchaser from the patient and patient from the health care service, and whilst purchasers are charged with acting in the interests of the patients, there appears to be no consistent effort to determine what is considered as acceptable by the patient (Frewer et al. 2001; Robinson and Thomson, 2001). In the UK great emphasis has been attributed on patient participation since the publication of "Working for Patients" (DoH 1989) and the identification in the "Patient's Charter" (DoH 1991) of the greater need for public involvement in health care decisions, and more recently "Learning from Bristol" (DoH 2006): "NHS care has to be

shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS works” (DoH 2000a, p88).

Tritter et al. (2004, p10) assert that user involvement is also increasingly important in cancer services. In 1995, the publication of the Calman-Hine Report, A Policy Framework for Commissioning Cancer Services (DoH 1995), set the tone for the reform and reorganisation of cancer care and established the ideal of patient-centred cancer services. More recently, this approach has been developed in the NHS Cancer Plan (DoH 2000b), which states that cancer networks need to take account of the views of patients and health professionals when planning services (DoH 2000b, p69).

With regard to the acceptability of care, several commentators have highlighted the idea that health service provision needs to be acceptable not only to the patient, but also to the staff who are the direct providers of care, and who may also become patients at various times during their lives (Shafique-Sajid 2007). However, this acceptability has also to relate to the willingness of the purchasers to finance the service, yet there has been no concerted attempt to delineate the concept of acceptability, let alone to attempt to align the different concepts of acceptability which may exist in relation to purchaser, provider and patient. Despite the assurance from the MoH in Cyprus and the independent experts that greater patient participation will be encouraged in the NHIS, there will be a need for systematic attempt to determine whether or not services will be, in fact, more acceptable to patients than before the implementation of the NHIS (Illiades 2007). Although it might be supposed that the acceptability of health care provision could in some way be determined by patients’ expression of satisfaction or dissatisfaction, this can be a notoriously misleading measure in terms of reliability and validity (Bond and Thomas 1992; Cleary and McNeil 1988).

iv. Efficiency

Efficiency is defined as “the ratio of the observed level of attainment of a goal to the maximum that could have been achieved with the observed resources” (Evans et al.

2001, p2), and the problems associated with measuring efficiency highlight the difficulties associated with quantifying what is essentially a human service. However, the efficiency dimension of quality is one which will remain an important issue, as the demand for health care resources continues to exceed the supply. This problem of supply and demand has recently become more apparent in Cyprus due to the opening of the “borders” with the occupied north part and the opportunity that was provided to the Turkish-Cypriots to freely use the health care services in the south (Athanasiaides 2006; Kasinidou 2006a). Although, as discussed, certain performance indicators have been devised, such as waiting times, which are used to measure the efficiency of the services provided, these remain very basic measures which can be seen to fail to incorporate all of the factors which relate to efficiency. The primary techniques for evaluating efficiency in the NHIS include (a) Cost minimisation³⁹, (b) Cost effectiveness⁴⁰, (c) Cost benefit⁴¹ and (d) Cost utility⁴² (HIO 2007b, 2007c; MoH 2006).

In addition to the concerns being raised by these strategies there is also an ethical consideration in relation to the efficiency component of quality. Taking into account the fact that in Cyprus there are limited resources, as there always will be whilst health care demand continues to outstrip health care resources, then rationing decisions have to be made. If maximum efficiency is to be achieved, then those decisions could severely disadvantage the old, the disabled, the poor and those suffering from diseases which can not be cured. Whilst care and palliative procedures can produce benefit for such groups, there is a risk that such benefit may be discounted if “cure” is taken as the main or only criteria of effectiveness.

Decisions of this sort would not, of course, be readily acceptable to professionals, politicians or the public, and so whilst efficiency is sought, there appears to be an implicit understanding that it is sought only to a certain, unspecified, level. Although techniques can be identified for measuring efficiency, these are much more explicit in

³⁹ Entails achieving the required outcomes at the least possible cost.

⁴⁰ Efficient service provision is judged to be that which achieves greatest success for each unit of cost.

⁴¹ It is necessary to devise strategies for comparing costs and benefits achieved and choosing the strategy which produce the greatest net benefit.

⁴² Efficiency is evaluated by examining the utility of the intervention.

being able to measure the cost of services. The benefits of services do not have such easily identifiable measures and therefore remain largely subjectively appraised, as objective measures remain underdeveloped.

In Cyprus, one of the central aims of the health services and the introduction of the NHIS is to improve efficiency through the implementation of an internal market model. This decision made by the NHIS specialists was driven mainly by the belief that as hospitals will compete for service contracts so efficiency would improve. This is based on the principle that hospitals will develop those strategies to ensure that they will not price themselves out of the market. However, for this to be achieved (or be probable to be achieved) it is necessary that certain conditions are taken into consideration and satisfied. These include (a) establishing that a high cost hospital is so because of inefficiency and not because of any other factors, such as local conditions, (b) moving patients from high cost, inefficient hospitals to low cost, efficient ones may raise resistance from patients that refuse to be treated in anything other than their local hospital, and finally (c) that the cost data which is used to determine efficiency is both accurate and reliable.

The claims that the health services will function more efficiently with the implementation of the NHIS is largely focused on improvements in certain performance indicators such as waiting times. It is likely that initially better value for money will be achieved, as the amount of health care provided would seem to be rising more rapidly than the amount of resources being utilised (Polyneikis 2007). However, as a measure of quality these performance indicators are lacking in substance as they fail to consider all three elements of quality and the possibility exists that if one element improves another may deteriorate (Donabedian 1980). Unless all three elements are monitored this may not be detected.

v. Effectiveness

In relation to effectiveness, it can be seen that there is a need to move beyond measures which focus on measuring the changes in health status. With the health services

experiencing difficulties in comparing the actual achievements with those intended there is a need for setting explicit aims and objectives in terms of measurable outcomes for successful decisions to be made in relation to the effectiveness of health service provision. Polyneikis (2007) has identified several problems when attempting to measure the effectiveness component of quality in the Cyprus HCS. Firstly, the fact that the aims of health care providers are often stated in rather vague terms, using concepts such as “meeting need” or “quality care” without expressing this in terms which can be measured, complicates the successful measurement of effectiveness. Secondly, providing quality services can not be related with effectiveness. This is based on the possibility for a hospital to be effective but to provide services which are inappropriate or under-used by the patients of that region. An example of this includes the provision of cancer care services in Nicosia by the BOC Oncology Centre, however, the vast majority of its services are being used by patients coming from cities other than Nicosia. Thirdly, measures aiming at effectiveness do not take into account the cost of achievement. Therefore in order for such measures to be used as measures of quality these should be used in conjunction with efficiency measures. Finally, there is a difficulty of linking cause with effect, therefore improvements in effectiveness could be related to factors other than the strategies employed to achieve this benefit.

Measuring the effectiveness of health service providers in terms of outcomes has been, arguably, the least developed measure of quality, a deficiency which has been identified, but as yet not rectified (Brook et al. 1996; Doorey et al. 1992). Although in the past the effectiveness of care has largely been evaluated by measuring the adverse outcomes of care such as perioperative mortality rate, or hospital acquired infections, and such information remains valuable, there is also a need to evaluate the positive effects of care. To determine the quality of outcomes of health care interventions requires the explicit definition of aims of care in terms not only of health status, but also in terms of well-being.

In addition to the problems which exist in relation to the outcomes of health care, there also needs to be a consideration of how structure and process factors might influence the

quality of care; factors which relate to two of the other three elements of quality. The structural elements of quality can be more easily measured than the elements of process and outcome, and so data is more easily available. Several structural aspects of care which relate to quality have been identified; one common measure used in Cyprus and elsewhere is to relate numbers of specialists (physicians and nurses) available in relation to population. However, the lack of a consensus as to the numbers of specialists required adds to the difficulty that such a measurement entails. However, these measures are not of none use at all. Such measures make it possible to compare the distribution of resources across the country and identify any inequalities in distribution which in turn will create inequalities of access.

When considering the process element of health care quality, the focus turns from the macro elements of the organisation to the micro elements of the interaction between the patient and the direct provider of the health care intervention (Hogston 1995). The importance of this interaction is well acknowledged in the literature as being the foundation on which quality of care is derived and judged, and so it is evident that the interpersonal as well as the technical component of care is one which determines the patients' perceptions of the quality of care they receive (Lichtman et al. 2001). Therefore the way in which health care professionals practice has a significant impact on the quality of care, and factors which can be seen to disrupt this practice, or impede the interpersonal interaction between professional and patient, will have a detrimental effect on that quality of care (Hogston 1995, p122-123).

It has often been suggested that the effects of stress on those providing care has proven to be such a disruption (Tankha 2006). The issue of stress in relation to nurses has been well researched both in terms of cause and effects (RCN 2005). When considering the causes of stress, lack of support, excessive workload, organisational and management issues, poor relationships and poor working conditions or facilities have all been identified (Badger 2005; Cassem and Hackett 1975). The effects of stress in relation to the quality of care that nurses deliver has also been explored, and one such effect is seen to be a shift in the way they view patients, from positive and caring to negative and

uncaring, another is the avoidance of decisions, problems and changes, areas which clearly illustrate the relationship of professional stress to quality of nursing care.

Another process factor which was found to positively influence the provision of quality health care is the pattern of work organisation, and a system of work which promotes personalised care (Pongsupap and Van Lerberghe 2006; Suhonen et al. 2000). The provision of a personalised system of care is likely to have serious cost implications, and therefore as the drive for efficiency gains momentum, the possibility exists that conflict will emerge between two of the components of quality – structure and process (Suhonen et al. 2004).

vi. Appropriateness

The task of determining appropriateness of care can also be problematic because beyond the professional perspective it also needs to include the perspective of the patient and the perspective of the society as a whole (Rowell 2004). From the professional perspective, despite the drive towards evidence-based practice (Gross 2000), there is little consideration of the health care interventions of nurses, or the range of paramedical staff involved in the direct delivery of care to the patient (Cronenwett 2001). There must be wide variation in what nurses and other health care professionals believe to be appropriate care in that there is wide variation in rates of procedures between areas, between hospitals and between individual practitioners (Polyneikis 2006).

Appropriateness of care incorporates not only utilisation, but also under-utilisation of health care services (Poulos and Eagar 2007). The drive towards evidence-based care has attempted to address the issue of appropriateness of care, through the development of recommended protocols for particular clinical conditions, the issuing of clinical guidelines, and the monitoring of adherence to such guidelines and such strategies are becoming more ordinary in hospitals (Lichtman et al. 2001; Lohr and Carey 1999).

The level of knowledge and understanding, but also by the values and belief systems of the patients is what determines their perception of appropriateness of the health care

(Rowell 2004; Haskin and Marx 1988). In relation to society's perspective, a number of influences including economic, political, social and cultural factors determine the appropriateness of health care. As society undergoes change so will the social view on the appropriateness of a wide range of health care interventions.

Critique of the strategies for quality assurance in the NHIS

Reviewing the strategies by which the MoH in Cyprus assures or plans to assure the quality of care provided across the hospitals and health centres, the following observations have been made:

(1) The structures⁴³ have been set up to perform formal and informal inspections in relation to the health care services provided. However, there are certain limitations to inspection as a mechanism of quality control (Polyneikis and Kalos 1992) such as the fact that inspection visits are infrequent⁴⁴, and therefore can not evaluate the process of the care which is carried out. Moreover, in certain circumstances the inspector may be employed by the same authority responsible for the services being inspected. Finally, inspections are usually structured around a given set of criteria, and offer little opportunity for the views of patients to be considered.

(2) There is a need for introducing a procedure for conducting regular reviews of health services. Whilst such reviews provide a useful amount of service information, as a mode of quality assurance they are fairly limited:

- Although the review may have been developed with reference to professional staff and patients, this is the province of senior management, therefore does not seek the views of either the health care professionals or the patients.
- Reviews attempt to capture a broad picture of the organisation at the time at which the review is taking place however; it is questionable that the review procedure, in itself, will have any impact on the quality of care provided.

⁴³ Ministry of Health 2001 – N.89 (1)/2001

⁴⁴ This is mainly due to the understaffing of the inspection service as this is reported in the 2006 Ministry's of Health yearly report.

- Reviews are largely concerned with issues of efficiency and budgeting, and pay little attention to other issues, such as access, effectiveness, equity, acceptability or appropriateness all of which seem to affect the quality of the nursing care provided.

(3) Performance indicators have been increasingly used to judge performance, but whilst providing a wealth of statistical data, the usefulness of this can be questioned as a method of quality assurance (HIO 2007b; MoH 2006). This lies in the fact that they take no account of the sophistication of local information systems, nor of differing priorities, their quantitative nature puts the focus on outputs rather than inputs and finally the determination of the standards used to construct performance indicators does not involve the patient.

(4) Patient satisfaction surveys began to be used as a measure to evaluate the quality of services nationally (Polyneikis 2006) and internationally (Quintana et al. 2006; Raftopoulos 2005). In the U.K. such surveys have been widely used, over a long period of time, to evaluate the quality of services (Crow et al. 2002; Sitzia and Wood 1997), and although such mechanisms may be useful they, too, have their limitations:

- The expectations of the individual determine the level of satisfaction, and so can not claim to be an objective evaluation of health care services.
- Patient satisfaction surveys methodologically rely on questionnaires, the timing of which is likely to have a major effect on the results.
- The assumption is made that patients have adequate knowledge of the available alternatives.

Reflecting on the ways in which attempts have been made to set up systems to assure quality, it can be argued that a diversity of strategies has been or will be utilised over time. However, none of these strategies can be seen to have provided a complete answer to the intricacy of quality service provision.

Attaining quality of care in the NHIS

Improving the quality of care provided by the health services was a key aim of the NHIS, one which has been subject to much debate and speculation but little in the way of in-depth evaluation. When examining the key components of quality there can be seen to be some potential improvement resulting from the implementation of the NHIS (Polyneikis 2006; Golna et al. 2004)

The further the future effects of the NHIS on the quality of health care are explored the more unclear and uncertain the picture becomes. Information is partial and in many cases can be seen to be structured by ideology rather than by objectivity. Without doubt there have been improvements in quality in some areas and deteriorations in others, but what is lacking is a systematic review of quality across the NHIS (Filippou 2006). Quality is in itself a complex and dynamic concept, and the NHIS a complex and dynamic organisation, and it may well be unrealistic to hope to achieve more than an idea of general trends in quality, even though the notion of measurability remains important and will continue to develop.

From a practical perspective, determining quality health care is complex, and whilst clinical audit is now well established, and patient satisfaction surveys commonplace in Cyprus, there remains little, if any, consensus as to the nature of what is being measured by such programmes (MoH 2006). Although the importance of the views of patients on the quality of health care services has been well recognised, the incorporation of their views into service planning has remained problematic (Illiades 2007).

At this point of time (2007) there have been no attempts by the health services in Cyprus to obtain patients' views about their nursing and medical care in relation to quality. Although a few studies have been carried out in Cyprus mostly on a personal basis and initiative (Charalambous and Papastavrou 2006), these have remained on a local scale, and much of the work in relation to service provider surveys of patient satisfaction remains unpublished. What is significant in such work is that; the one issue which consistently emerges as being viewed as unsatisfactory is the area of communication

between health care professionals including nurses and patients. This is illustrative of the importance which patients place on the one to one interaction between themselves and the health care professionals, and which, it can be argued, is an area which is poorly reflected in the existing quality measures in the NHIS. The ways in which such process oriented measures could be developed, however, remains unclear, and marginalised in the current drive towards evidence-based practice and health status outcome measures. Despite the introduction of a broad spectrum of quality initiatives in the health services, quality is not a concept which has a shared meaning between, and even within, groups of health care staff including nurses.

In Cyprus it has been recognised that the understanding of the term quality differs within and outside the NHIS (Polyneikis 2003). The gradual evolution of a definition of quality within the NHIS has negated many of the benefits which can be obtained from explicitly focusing on the attainment of quality in service delivery. Whereas in organisations outside the NHIS the customer is viewed as “king⁴⁵”, within the NHIS the patient’s position is less clear. There is a fundamental problem in adopting quality frameworks devised for the commercial market, into a quasi-market organisation, as a struggle emerges to ascertain whether the needs of both purchasers and patients can be met by the NHIS. As purchasers, private health establishments and GPs utilise different criteria for determining the quality of health care than do patients, so in a real sense the NHIS is required to attempt to resolve these differing criteria in the attempt to deliver a quality service.

Phillips et al. (1994, p17) assert that “quality” is a highly personalised concept and the important message for health and care services is to begin to ask questions about whose quality ought to be controlled or appraised. A further reason why quality is such a contentious issue, within the NHIS, is that determining the quality of health care is a fundamentally different problem from that of determining the quality of a product. Whilst the quality of a product may be measured by assessing its performance in a given range of areas, the measurement of the quality of health care can be seen as much more

⁴⁵ Motto: *o pelatis exei panta dikaio* – the customer is always right.

subjective, and the desired outcomes for patients of the NHIS are likely to be considerably more diverse than the desired outcomes of the purchasers of a product.

It has to be recognised that although many who use health care services will seek the eventual return of full health, for many this is not a possible goal, and even if it were, the construction of viable outcome measures for this would necessarily be subjective, as health is a concept which is difficult, to define in measurable terms (Murray et al. 2003). This is why the assumption can not be made that the only benefit of health care is an improvement in health status. Therefore a range of alternative sources of benefit need to be recognised in order to capture the quality of health care services as Shackley and Ryan (1995) assert. Such benefits may include comfort, reassurance, information, and autonomy, the importance of which on their utility or wellbeing can only be determined by the patient. This question of subjective quality evaluation highlights the difficulties which occur when trying to adopt the commercial definition of quality to act as a framework for evaluating care.

The nurses' role in achieving quality of nursing care

Nurses comprise the largest group of health care providers in both the public and private sectors with the patients having more contact with professional nurses than any other health care professional. Nursing, as a vital component of the health care delivery system, needs to reaffirm its purpose as a practical discipline in assisting patients to achieve positive health care outcomes. Changes in the nursing workforce as well as changes in the Cyprus HCS have prompted renewed efforts to ensure that hospitalised patients receive quality nursing care. In response to these efforts nurses in Cyprus are increasingly aware of the need to focus more closely on indicators of quality (Leontiou 2007; CYNMA 2006). In Cyprus, models for assessing quality of care are not well developed. There are no national standards of nursing care and nursing practice, and limited indicators to measure the quality of nursing care delivered in hospital settings (Polyneikis 2006; Charalambous and Papastavrou 2006). Caring for patients with cancer in Cyprus appears to be difficult for the nurses even if this claim is based on casual discussions between nurses and hardly on any empirical evidence. Similarly, in the

international literature there are only a few studies that have focused on those problems experienced by nurses in these settings (Rustoen et al. 2003; Eriksson et al. 1999; Fitch et al. 1999).

In addition to these problems experienced by nurses, health care, including cancer care, is in the midst of a revolution driven by strong forces of cost containment and competition (Wen and Gufstanson 2004). Cancer care providers are expected to both improve performance and reduce costs; not as a one-time event but as a way of life. However, according to the Cyprus Association of Cancer Patients and Friends (2004), these improvements are unlikely to occur without a much better understanding of patient and family needs and the factors that influence them. Similarly, the Cyprus Anticancer Society (2005) comments that only when these needs are fully understood, can interventions be designed to improve adherence and reduce waste and rework. These pressures to contain costs occur at the same time that patients are taking a more active role in their care. Such trends are manifested in the growth of not only alternative and complimentary care, but also in the growth of e-health. Patients with cancer and their families are searching for alternatives, in part because the health field does not fully understand and respond to their needs.

Conclusion

The experience of patients with cancer, illustrates the implications of not designing delivery systems around a clear understanding of patient needs. Explicitly, quality of nursing care is a multidimensional and complex concept that is difficult to define or measure. Even if strategies have been or will be applied to assure quality in the health care context of Cyprus these appear to be insufficient and in any case out of focus in relation to what really matters to the patient. Therefore, many issues need to be taken into consideration in the process to define and achieve quality nursing care in cancer settings, and in the case of Cyprus; culture is one major factor that needs in depth exploration as to the way it influences the delivery and understanding of quality nursing care. In the next chapter, the ethnohistory of Cyprus is explored in order to identify those aspects that may influence the meaning and experience of quality nursing care.

CHAPTER 4

Ethnohistory - Laografia⁴⁶ of Cyprus

Introduction

According to Leininger (2002, p190) “the study of the ethnohistory has provided a body of theory-based research knowledge for the growing discipline and practice of transcultural nursing”. It provides some entirely new ways to care for people of many different cultures (Leininger and McFarland 2002). With a rich background in history and culture, Cypriots provide an excellent example where the study of their ethnohistory can provide valuable information on the way people comprehend and experience illness, their health beliefs and values thus assisting in the identification of the best strategies to introduce changes for the promotion of quality nursing care.

Cyprus has its roots in the Classical Greek period dating back 100 centuries into the mists of prehistory and legend. Cyprus lies at the crossroads of great civilisations. It has had a tumultuous past; its history is primarily that of occupation with the conquerors and rulers placing a strong influence on the Cypriot character, leaving an impression on the land, in the arts and forming the bedrock of Cypriot culture.

For Leininger, culture is a process of “learned, shared, and transmitted values, beliefs, norms, and life practices of a particular group that guides thinking, decisions and actions in patterned ways” (1988, p156). Rather than simply the presence or absence of a particular attribute, culture is understood as the dynamic and evolving socially constructed reality that exists in the minds of social group members. It is the “normative glue” that allows group members to communicate and work effectively together (Hudelson 2004, p1). A number of studies have looked, for example, at the relationship between a culture and quality-related outcomes, such as hospital performance indicators (Gifford et al. 2002), nurse turnover (Meterko et al. 2004), and patient satisfaction (Scott et al. 2003). Research has shown that health perceptions mirror quite accurately de-facto

⁴⁶ According to Panaretos (1977, p1) “Laographia” is the science that aims to explore the traditional manifestation of the spiritual, social and material lives of historic nations

health while reflecting at the same time cultural norms of health (Lundberg and Manderbacka 1996). Health perceptions are the ways that people comprehend and reflect on their health (Sholkamy 1996). These determine people's behaviour and their decisions about when to ask for help. Health behaviours are considered to be activities undertaken by people who believe they are healthy in order to prevent future health problems, such as eating a balanced diet that is low in cholesterol and fat, and exercising regularly. Both health perceptions and health behaviours are rooted in the culture of the people (Leininger 1995).

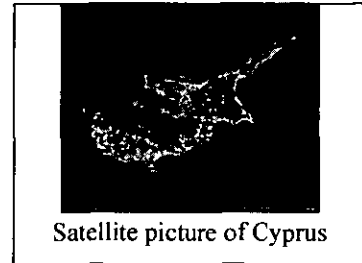
The researcher who deals with such cultural analysis (as in my case in this study) must be aware of the cultural frame created by their own culture and language backgrounds if she/he wants to understand another culture with "typical" characteristics. In the words of Carroll (1988, p4) "One must be aware of his own culture, of his cultural presuppositions, of the implicit premises that inform his interpretation, of his verities".

Helman (1990) also believes that our cultural background has an important influence on many aspects of our lives, including our beliefs, behaviours and attitudes to illness, pain and other misfortunes, all of which may have important implications for health and health care. Cooley and Jennings-Dozier (1998) in the same light are proposing that culturally-derived beliefs about health and illness, use of a lay referral system, use of folk treatments and the importance of family, community and spiritual support, are some of the cultural concepts that must be considered.

An ethnographic study by Papadopoulos (1999a) to investigate the health and illness beliefs of Greek-Cypriots living in London revealed themes related to cancer and nursing care. Cypriot culture, family beliefs, and religion contribute significantly to the understanding and management of cancer and the quality of the nursing care. Furthermore one needs to take into consideration that culture is not something external to him/her, he/she creates it just as it creates him/her; it is no more outside him than his thoughts; it produces him and he produces it.

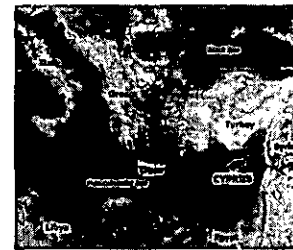
The origin of the name “Cyprus”

According to Pantelidou and Chatzikosti (1992) the name Cyprus has a somewhat uncertain etymology. Newman (1940) asserts that the word “Cyprus” comes from the Greek word “κυπάρισσος (*kyparissos*)” meaning “cypress tree”. Maier (1968) suggests that the name stems from the eterocyprian word for copper. The name of the Greek goddess Aphrodite also appears as a possible suggestion according to Rogerson (1994) and the PIO (Press and Information Office) (2003). The rationale for this suggestion is justified by the mythological tradition based on which Cyprus is the mythical birthplace of Aphrodite.



Geographical Position

Cyprus is the third largest island in the Mediterranean Sea after Sicily and Sardinia (Rogerson 1994). The latitude of Cyprus is 34° 33'-35° 34' North, and its longitude 32° 16'-34° 37' East. Its 9,251 square kilometres encompass citrus and olive groves, pine forested mountains, and some of Europe’s cleanest beaches. Cyprus is the easternmost island in the Mediterranean Sea. It is approximately 105 kilometres west of Syria, 75 kilometres south of Turkey and 380 kilometres north of Egypt (PIO 2003).



Size of population, ethnic make-up and languages⁴⁷

The population of Cyprus is 793,100 of whom 80.7% are Greek-Cypriots⁴⁸, 87,600 (11.0%) are Turkish-Cypriots and 66,000 (8.3%) foreigners residing in Cyprus. The density of the population is 86 persons / sq km (CSS 2001). However, this statistical information does not include the occupied north territories of the Republic of Cyprus.

⁴⁷ Statistical information do not include the occupied north territories of Cyprus unless otherwise stated

⁴⁸ Including Armenians, Maronites and Latins

The language of the Greek-Cypriot community is Greek and the community adheres to the Greek Orthodox Church of Cyprus. The language of the Turkish-Cypriot community is Turkish and the community adheres to Islam (MoFA-Ministry of Foreign Affairs 2006).

Nicosia⁴⁹ is the capital of Cyprus with a population of 206,200 (end of 2001) in the sector controlled by the government of the Republic of Cyprus. It is located in the centre of the island. During the 1974 Turkish invasion 36% of the island's territory was occupied and the capital was literally cut in half.

The second largest town is Limassol⁵⁰ in the south, which has around 161,200 inhabitants. It is the main commercial port in Cyprus and an important tourist resort (CTO-Cyprus Tourist Organisation 2006).

Larnaca⁵¹ is located in the south-east of the island and has a population of 72,000. Larnaca is the island's second commercial port and an important tourist resort. To the south of Larnaca lies the International Airport. The city of Larnaca is well-known for its picturesque sea-front which includes rows of palm trees (CTO 2006).

Paphos⁵² in the south-west with a population of about 47.300 is a fast developing tourist resort, home to the island's second International Airport and an attractive fishing harbour. The Turkish invasion and occupation of the major tourist resorts of Keryneia and Ammochostos led to major investments by the government and the private sector in the district of Paphos.

In the Turkish occupied area, the town of Ammochostos⁵³, the hub of the pre-1974 tourist industry, is now a ghost town, deserted since 1974 when its inhabitants fled from

⁴⁹ Λευκωσία (*Lefkasia*) in Greek

⁵⁰ Λεμεσός (*Lemesos*) in Greek

⁵¹ Λάρνακα (*Larnaka*) in Greek

⁵² Πάφος (*Pafas*) in Greek

⁵³ Αμμόχωστος in Greek

advancing Turkish troops. The towns of Keryneia⁵⁴ and Morphou are now inhabited exclusively by Turkish-Cypriots and Turkish settlers.

Church of Cyprus

The Orthodox Church of Cyprus is one of the oldest autocephalous churches in the eastern communion (Encyclopaedia Britannica 2006). Its independence



was first recognised by the Council of Ephesus (431 A.D) and reaffirmed by the Council of Trullo (692). The Archbishop received the three privileges, still valued and practiced: namely to sign his name in cinnabar; to wear purple instead of black robes under his vestments; and to hold an imperial sceptre instead of a normal episcopal crosier (PIO

2003; Papageorgiou 1962).

In the following centuries Cyprus was invaded by the Arab with several cities been sieged. The Archbishop escaped to the Hellespont⁵⁵ where he and other survivors found refuge, and where they established the city of Nova Justiniana⁵⁶. The succession of the Franks by the Venetians in 1489 did not bring any change to the status of the Orthodox Church. The Orthodox Church was recognised by the Ottoman as the only legal Christian church with political authority over the Christian population. The Church assumed the responsibility for preserving the faith, the national identity, the customs and the traditions of orthodox Greek-Cypriots. As a result, the churches were not anymore simply places of worship but were converted to places of ethnic inspiration and schools (Pantelidou and Chatzikosti 2003, p106).

The coming of the British in 1878 allowed more freedom in religious matters. However, the initial enthusiasm for the arrival of the British gave way to scepticism and disappointment when the British Administration introduced restrictive laws on the management of the Church and other areas of national activity. According to Pantelidou and Chatzikosti (2003, p222-223) this interference led to riots organised by bishops who

⁵⁴ Κερύνεια and Μόρφου in Greek

⁵⁵ The Hellespont/Dardanelles, a long narrow strait dividing the Balkans (Europe) along the Gallipoli peninsula from Asia Anatolia (Asia Minor).

⁵⁶ Νέα Ιουστινιανή in Greek

were also members of the legislative assembly. As a consequence of this upraise, the Bishops Nikodemos of Kition, and Makarios of Kyrenia were exiled and restrictions were imposed on the election of the Archbishop.

In 1950, Makarios III was elected Archbishop. Ten years later he became the first elected President of Cyprus.

A History glance at Cyprus

The historic wealth of Cyprus includes more than 10,000 years which are divided into several periods, starting from the Epipaleolithic age to the recent history of the island. For the purposes of this study it was not possible to provide detailed analysis of each period, therefore from 8000 B.C to 58 B.C the different ages of the Cyprus history were summarised in the following table. The more recent periods are presented in more detail later in this chapter.

Table 4.1. Summary of Cyprus early historic ages

Ages	Period	Characteristics	Developments
Epipaleolithic	8000-7000 B.C	Hunters-Gatherers	Invention of agriculture transformed mankind from family groups of mobile hunter-gatherers into permanent communities of farmers.
Neolithic or Stone Age	7000-3000 B.C	Well-built round houses of two stories	Use of pottery, stone, and presumably wood, for utensils and stone for tools
Chalcolithic	3900-2500 B.C	Discovery of Copper	Population growth and the emergence of social ranking
Bronze Age	2500-1050 B.C	Copper is widely exploited	Emergence of trade with other parts of the Eastern Mediterranean
Iron Ages	1100-700 B.C	Indifference for the sick and the handicapped. Aphrodite is the fertility goddess of the island.	<ul style="list-style-type: none"> • Migration of Greek-speaking peoples from the Peloponnese. • New cities were founded.
Assurian Rule	700-669 B.C	Epic poetry was popular. Use of bronze, iron and ivory in arts.	Tributes were collected from Cypriot kingdoms
Period of independence	669-564 B.C	Complete independence	Exuberant development
Egyptian Domination	565-546 B.C	Influence over the arts.	Cypriot kingdoms remained independent but had to pay tax
Persian Domination	546-333 B.C	Cyprus incorporated into the fifth satrapy of the Persian Empire.	King of Salamis, Evagoras I (411 - 374 BC).
Hellenistic Period	333-58 B.C	Arts flourished. Public works - theatres, gymnasiums were established. Paphos thrived as the capital of Cyprus.	Cypriot kings were granted autonomy. Cyprus was taken over by Ptolemy I in 294 BC after Alexander's death.

Cyprus under the Roman Empire (58B.C-330A.D)

The Roman Empire brought changes in relation to the social system, the government, the geopolitical structure as well as the health provisions. According to Rousou (1993) the Romans introduced their concept of the prevention of illness. They made efforts to keep the cities clean and preserve the environment. Their idea of maintaining health has also led the Romans to build gyms, sewer systems, aqueducts, watering systems as well as public baths (Rousou 1993).

Cyprus in 22 B.C as a senatorial province with municipal autonomy had the power to elect officials and a substantial degree of independence in religious and cultural matters (Newman, 1940). The cult of Aphrodite had never been forgotten; her temple in old Paphos has remained one of the most famous holy places of the Mediterranean. However, in the course of time, the cult of Aphrodite gave way to Christianity (MoE 1992). Eventually this fact led to the replacement of the goddess by the Panagia. The introduction of the Christian Philosophy has brought to the island the religion of love, compassion and respect of the person and provided the basis of the nursing practice influencing the care of the sick, the unregarded and the helpless (Anastasiou 2000; Rousou 1993).

Byzantine Period (330A.D-1191A.D)

Emperor Constantine of Byzantium had officially recognised Christianity in 313 A.D. In 391 A.D Emperor Theodosius ordered the closure of all pagan temples, ending this way the rituals at the Temple of Aphrodite in Paphos, though worship of Aphrodite continued (Vrioni 1990).

This period saw the discovery of the tomb and gospel⁵⁷ of St Barnabas by Archbishop Anthemios. This earned him great fame and privileges and led to Cyprus being granted the status of an independent church (Papageorgiou 1962). After the division of the Roman Empire (395 A.D) Cyprus remained subject to the Eastern, or Byzantine, empire at Constantinople (Zakinthinou 1953).

⁵⁷ According to St Mark, was handwritten by St. Barnabas

Cyprus under Richard I (1191A.D-1192A.D)

King Richard of England was on his way to the Holy Land participating in the Third Crusade when his fleet was scattered by a storm and took refuge in Crete and Rhodes (Pantelidou and Chatzikosti 1994, p51). Several ships with one having on board Johanna, sister to Richard, and his affianced bride, Berengaria of Navvare were driven to the shores of Cyprus, where they were wrecked and sank in sight of the port of Limassol whereas the crews who escaped to land were taken prisoners by the order of Isaac Commenus (Chatzioannou 1993). This led to a battle with Richard. The English knights defeated the Cypriots and the Cypriot nobles pledged allegiance to the king of England (Pantelidou and Chatzikosti 1994, p52).

Lusignan Period (1192A.D-1489A.D)

According to Chatzioannou (1993), a new form of political and social organisation, namely feudalism, was introduced by the Lusigans in Cyprus. The Latin Church was introduced and the Orthodox Church persecuted.

Gradually the Lusignan influence slowly weakened which led to recurrent raids on the island mainly by the Genoese and Mamelukes. Eventually, when the Genoese invaded Cyprus the Lusignans sought help from the Venetians. The Genoese were defeated and the Venetians occupied Cyprus for themselves.

Venetian Period (1489A.D-1571A.D.)

The Venetians constructed fortresses against the threat of an Ottoman invasion (Chatzioannou 1993). Venetian occupancy proved to be a difficult period for the Cypriots. Venetians faced Cyprus merely as a colony and their only concerns was the collection of taxes and maintain this important commercial centre (Pantelidou and Chatzikosti 2003, p62).

During this Lusignan and Venetian periods there are no indications of any organised provision of care to the sick and helpless. The care became primarily a responsibility of the family (Anastasiou 2000).

Turkish Rule (1571A.D-1878A.D)

The Ottoman Turks conquered Cyprus in 1571; an event which brought immense changes on the island and its people. The new regime put an end to the feudalism system and gave the Cypriots the legal ownership of the land they had worked for centuries. During the years of the Turkish rule there was a diminishing of the Greek population of Cyprus and at the same time an increase of Turkish settlers from Anatolia (Pantelidou and Chatzikosti 2003, p104).

In 1821 the Ottoman Empire was faced with rebellions over its Greek-speaking provinces. Cyprus participated in these rebellions under the orders of Archbishop Kyprianos who had already joint Philike Hetaireia⁵⁸ back in 1818. As a result the Turkish governor of Cyprus launched a crackdown campaign which led to the hanging of the archbishop and 485 other prominent members of the secret organisation (Pantelidou and Chatzikosti 2003, p115).

Cyprus remained under the Ottoman occupation until 1878 when the Sultan ceded Cyprus to the British, though it remained the property of the Sultan. When Turkey joined forces with Germany and entered the First World War in 1914, the British formally annexed Cyprus. In 1925, Turkey renounced all claims to the island under the Treaty of Lausanne and Cyprus was declared as a British colony (Pantelidou and Chatzikosti 2003, p187-188).

British Rule (1878A.D-1960A.D)

According to Hitchens (1997) one of the reasons for occupying Cyprus was the defence of the Suez Canal, in which Britain had acquired an interest. During their rule on the island the British had to deal with two political problems. The first was to contain the

⁵⁸ In Greek - *Φιλική Εταιρεία*: a secret organisation that planned to establish an independent Greek state out of the Ottoman Empire

desire of the Greek population for union with Greece, a long-lasting desire which materialised during the years of the Turkish rule. This resulted in the Turkish-Cypriots calling for division as a respond to enosis and the alleged attempt to being Hellenised. Therefore the British had to find ways to maintain the peace and harmony between the two communities (MoFA 2007).

The rise of the new nationalism in Ataturk's Turkey fired the Turkish-Cypriot resentment. This event alarmed the British, who clamped down on Turkish-Cypriot agitation. By the 1943 the Turkish-Cypriots had formed the KATAK⁵⁹ (MoFA 2007).

In the Greek-Cypriot community the demand for enosis never ceased. As an alternative the British attempted to introduce constitutional government designed to develop some participation without leading to enosis, however without getting a result. In the 1950s Greece began to accord it support on the international scene the Greek-Cypriot demand for enosis reached its peak. Regardless of the international pressure, "Britain did not respond as expected, which led to violence escalation with a campaign against the colonial power organised by EOKA⁶⁰ under Colonel George Grivas" (Pantelidou and Chatzikosti 2003, p232).

Additional to the political impact that Britain had over Cyprus, there was an impact on the healthcare system which is important in terms of this study's aims. This impact is discussed later in this chapter.

The Republic of Cyprus

Cyprus had gained independence in 1960, however shortly after serious differences arose between the two communities about the implementation of the constitution. As a result of this conflict, intercommunal fighting erupted in 1963 after which the Turkish-Cypriot withdrawn from the central government. The following year UN peacekeepers were deployed on the island (MoFA 2007).

⁵⁹ Party for the Protection of the Turkish Minority

⁶⁰ EOKA: National Organisation of Cypriot Fighters (*Εθνική Οργάνωση Κυπρίων Αγωνιστών* in Greek)

In 1974, a military coup was launched against president Makarios led by a group of Cypriots and with the support of the military junta in Greece. The coup gave Turkey the excuse it was looking for, and in July 1974, they invaded Cyprus in violation of the UN Charter and all principles governing international relations (MoFA 2007). As a result 36.7% of the island was occupied, 162,000 Greek-Cypriots who were forcibly expelled from this area became refugees in their own country and are still deprived of the right to return to their homes and properties. Many were killed and in addition about 1,479 Greek-Cypriots are still missing (PIO 2003).

Attempts to solve the Cyprus problem

Negotiations to solve the Cyprus problem have been going on intermittently since 1975 under the auspices of the UN (MoFA 2007). The UN began in 1999 another effort to find a resolution on Cyprus through direct talks between the representatives of the two communities. As part of this process, a detailed plan was presented for a comprehensive settlement. The Turkish-Cypriot leader, however, rejected the plan outright, leading the talks to collapse.

On 24 April, 2004 the two communities in Cyprus were asked to approve or reject the Annan Plan V (UN Secretary-General's proposal)(MoFA 2007). The Turkish-Cypriots approved the plan, but a clear majority of Greek-Cypriots rejected feeling that the finalised text was not balanced and did not meet their main concerns regarding security and the functionality and viability of the solution. On May 1st, 2004 the republic of Cyprus became a full member of the EU completing a long journey that lasted more than three decades (MoFA 2007).

Discussion

Reviewing the ethohistory of Cyprus one realises that the Cyprus culture is a mosaic of elements drawn from different cultures, European, Asian, Middle Eastern and North African. One might argue that Cyprus has experienced the positive and negative influences from other cultures, a concept that today is well known as "cultural diversity". The rulers and conquerors have each in its own way left their imprint on

Cyprus and its people. Their beliefs, values and attitudes have been shaped over the passing of time. Evidently, the ethohistory of the island has influenced how its inhabitants view the world and consequently how they view health and illness; how they care for themselves as well as their views on the care they receive from others. These influences have resulted in the configuration of a distinctive and complex cultural construct, often difficult to be understood by outsiders⁶¹.

What I can conclude from the distant and more recent history, geography, demography, politics and religion of Cyprus can be summarised to the following:

- Cyprus is a small island with a small population
- Although numerous rulers have passed through Cyprus the population remains primarily bi-cultural.
- The majority of the population are Greek-Cypriots. They have Hellenic roots and share history, culture, language and religion with the population of Greece.
- Greek-Cypriots have been fighting for their freedom to retain their civilisation throughout history. This facilitated the rise of collectivism in the Cypriot society which is preserved to this day, however, with many individualistic characteristics being introduced and hence forming an oxymoron combination of collectivism and individualism.
- Fighting against invaders provided Greek-Cypriots with common goals. Other characteristics of collectivist cultures that apply to Greek-Cypriots include:
 - Group loyalty overrides personal goals. It is evident in the Cyprus history that for the sake of the many the few were sacrificed⁶². This is to confirm that collectivism requires self-sacrifice, the subordination of one's interests to those of others.
 - Collectivists put high value on self-discipline, accepting one's social position, honouring parents and elders, and preserving public image for the group's sake.

⁶¹ Non – Cypriots

⁶² Cyprus history is full of examples of people giving their lives for the benefit of the society. The sacrifices of Grigoris Afxentiou during the fight against the British rule and the sacrifice of Archbishop Grigorios E' who was hanged by the Turks are exceptional examples.

- People tend to think in terms of long-term goals which benefit the whole group.
- Family integrity is of utmost importance. Children should live at home with parents until marriage. Aging parents should live at home with children.
- Religion has sustained the Greek-Cypriots identity through the ages. It has provided leadership and a moral compass.
- Cyprus is a country of conflict and contradictions: survival vs. freedom, religious guidelines vs. law, taboos and isolation vs. support and openness to those who “suffer” customs and tradition vs. modernity and diversity.

These issues have a relevance to health, illness, health services, nursing and cancer nursing the most important of which are presented here.

Turkish invasion and the impact on health

The Turkish invasion of the island did not only bring a blow to the people and their cultural heritage, but it also caused major problems for their HCS. The refugees were large in numbers, and the existing hospitals failed to meet the new challenge. At the time, Famagusta was by far the richest and most developed city in Cyprus possessing a large and modern hospital which provided services to Cypriots from all over the country.

Certainly the war and occupation changed the health scene on the island. For many years the state struggled to develop health services for its people. Many hospitals and health centres were built without a strategic plan or a vision for its future needs. In the new setting that was developing, the health services became centralised with minimal care offered to the rural areas. Moreover, in the light of the economic crisis that followed the war, there was no room left for specialised treatments such as cancer services.

It is only in the last 15 years that specialised health care such as cancer care began to evolve and is now offered widely to the Cypriots. However, little has changed in terms

of the design and provision of care. Services⁶³ remain centralised while a national strategy for cancer is lacking. This fragile setting that had been developed in Cyprus was recently shocked by two events. The first was the opening of the so called “borders” of Cyprus in April 2003, this way allowing free passage to and from the occupied areas and vice versa, and the second event being the Cyprus accession to the EU. The harmonisation process with the EU both at the pre and post accession periods called for major revisions on the HCS of Cyprus. Some of the issues that had to be addressed were the highly centralised provision of services, the bureaucracy, and the improvement of access and quality of services (Polyneikis 2003).

As was earlier discussed, the relaxation of the enforced separation of the two communities meant that Turkish-Cypriots from the north could access the free southern part of the island. One of the most significant outcomes of this was the impact on the health services in the south which began receiving large numbers of patients from the north. This sudden increase of demand found the health services ill-equipped to respond effectively.

In the literature there are studies (Reiche et al. 2005; Osterweil 2003) that show the relation between cancer and stressful life events. Magne (2006) asserts that stressful events can increase the possibility of people developing cancer. War and its consequences are considered to be among the most stressful experiences that a person can live. The history of Cyprus is that of war, occupation and suppression and its people have experienced the results of these stressful events which impacted on their health (Loizos and Constantinou 2007). This resulted in cancer being one of the main killers of this country with statistics showing a constant increase in numbers.

The notion Cypriots have of “freedom”

Cypriots have been fighting for their freedom for most of their 100 centuries of history. Rulers over the years have made them slaves, sold them abroad, took all their belongings, and denied them the right to govern themselves. This made Greek-Cypriots

⁶³ Specialised treatments such as radiotherapy and chemotherapy

people who valued freedom and autonomy. It can be argued that these characteristics influence all aspects of their lives including their health and illness. With increasing levels of education and other empowering skills such as the use of internet the Cypriot population is becoming more autonomous and therefore reluctant to accept any decision imposed on them by their health professionals including nurses. They want, and sometimes demand to be informed and actively take part in decision-making processes.

Cypriot's attitudes towards change

Upon reflection, the effects the many conquerors of the island, have had on the Cypriots over time, are considered responsible for many of the behaviours developed by its people. Cypriots have developed a high resistance as far as it concerns the status quo in every aspect of their lives, and change is often seen as a threat to the equilibrium of their lives (Zetter 1999). On the contrary, some researchers assert that Cypriots are more adaptable because of their history of permanent change in conquerors (Kliot and Mansfeld 1994). Resistance to rulers shows their fighting spirit for survival and challenge of oppressors.

The health care area and particularly nursing has experienced resistance from the staff to proposed changes over the years such as the introduction of a different patient evaluation system and the introduction of mentorship in nursing education. However, I do acknowledge that failure to introduce these changes might have also been the result of lack of consultation about the change and the lack of preparation to cope with the impact of change. In the same light, nurses tend to believe that many aspects of the care they provide are not part of their duties and quite often they avoid performing them. An example with significance to this study is the difficulty nurses face when they need to emotionally support patients with cancer (often confessed in casual discussions among colleagues). Therefore, this emphasises the fact that any strategic framework or guidelines proposed need to be introduced very carefully and in full consultation with them, allowing for an "adaptation" period. This period will allow the change agents and nurses to prepare for the reforms and thus increase the possibility of accepting and adopting them.

A wide body of literature (Shanley 2007; Wiest 2006; Cork 2005; Baulcomb 2003) asserts that there are a number of factors (drivers) that help to achieve change as well as factors that may impede change (restrainers). The availability of an appropriate rewarding system, the involvement of key people in the change process, good planning and preparation and willingness to change are drivers that facilitate the introduction of change. My involvement in research studies in the field of nursing in Cyprus taught me that the use of drivers is essential if change is to be successfully introduced. Specifically, the nursing services division attempted to introduce a new “holistic care plan” for the care delivered to patients. Unfortunately, the proposed change was not well-prepared, nurses were not appropriately informed, there were insufficient clarifications as to the need for change, and there were inappropriate stimuli (i.e. reward system) for the staff. In the light of these circumstances the proposed plan failed to be introduced successfully to the hospitals in Cyprus.

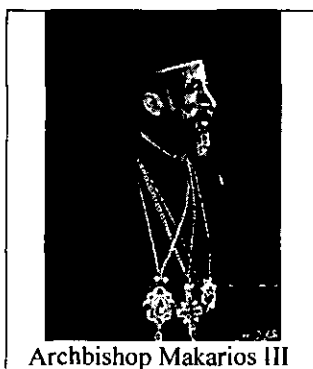
Religion and the Church of Cyprus

The essential role that religion and the church of Cyprus has played over the years, and is still playing, on the people of Cyprus as a whole, is indubitable and history stands as a proof to this claim. This very close relationship becomes, even stronger when people find themselves in need, or in situations where their health is seriously threatened such as by cancer. Even people who are not deeply religious, when faced by such situations they themselves or a member of their family will turn to God and the church for divine intervention.

Most of the Cypriots’ beliefs and values, in relation to health and illness, are based on very early views of the church where many still remain unchanged. Based on Bagwell’s (2005) viewpoint, the early church viewed sickness as punishment for sin; healing could only occur through the grace of God as a miraculous event. It was believed that Christian charity to the poor and afflicted served as a means to receive God’s forgiveness and ensure salvation. As a result of this belief, hospitals in the 4th and 5th centuries evolved as places for charitable works for the destitute, based on Roman

military camps known as nosocomia, designed to care for soldiers wounded in battle. Rather than providing temporary care, these facilities provided long-term care for the ill and were largely staffed by caring, but untrained, Christian women (Bagwell 2005, p874). The Christian Orthodox Church continues to hold the view that illness is rooted in sin. For example father Porfyrios (1906-1991), a modern saint of the Greek Orthodox Church, in a letter addressed to his spiritual children asserted that “However, with the concession of God, because of my sins, I became severely ill” (Tzavaras 1999, p15).

Religion and church are closely connected in the lives of the Cypriots. There is a multiplicity of less extreme situations and examples whereas one can visualise the importance of religion to Cypriots, one of which is the connection between religion and



Archbishop Makarios III

state. Archbishop Makarios III was the first president of the newborn republic of Cyprus and was considered as “*ethnarchis*⁶⁴” by the people of Cyprus. His election was no surprise since church leaders have always played an essential role in leading the Greek-Cypriot ethnos. This phenomenon remains in contemporary Cyprus even though its expression has changed. Nowadays, the Archbishop and Bishops continue to express political views and have discussions with the leaders of political parties and foreign politicians.

The church continues to influence the Greek-Cypriot population not only in terms of their views on national political matters but on most aspects of their lives. The church remains the point of reference for all moral issues from birth to death (Fotiou and Efthimiou 1990).

The role of family in health care.

Family is seen as a supportive agency during the course of illness. Cypriots know and take for granted that, if and when an illness occurs, they can rely on their family to help them through. The reasons for this are evident in the Christian values, historical

⁶⁴Ethnarchis is commonly understood as the leader of the nation and the church.

experiences and the social values that lead people to this behaviour. Greek-Cypriots are Christian orthodox (majority) and for Christianity the constitution of “family” needs to be valued, protected and promoted. Traces of this belief can also be found in the 10 Commandments given by God to Moses in mountain Sinai, the fifth of which refers to family “Honour your father and your mother”. Cyprus and its people managed to maintain their identity against the many raids, occupations and attempts to change their religion and their character by relying on the family and church. The “family” constitution was preserved as the strong “cell of the society” by maintaining strong links with its members and acting as a stronghold. People usually lived together, worked together and as a strong group with common opinions and goals resisted outside intrusions. Church and family also played a vital role by teaching the Christian and ethnic values, norms, language and history.

Despite the rise of individuality as a concept in the Cypriot society, the role of the family still remains particularly important and valued by the Cypriots. The collective grounds of the Cyprus society play an equally important role that one needs to take into consideration and more importantly, respect. Taking health care as the example, the decisions regarding the patients’ health need to be taken in collaboration with the other members of the family. If the patient is very old and unable to decide for himself/herself then usually decisions and interventions are made by senior or powerful members of the family network – usually the father – rather than by the individual (patient). Something I observed during this study was that in most cases other members of the family demanded to be present during the interviews, and even sometimes “corrected” or simply added to the patients’ opinions. It might seem as an out of the ordinary behaviour, however, it is considered natural to the Cypriots.

Very often the support offered by the family takes the form of emotional or spiritual support, but in many cases relatives can offer other forms of support to the patient and his/her family such as hospitality to the children during the period of the illness or financial support. Therefore, the patient relies on and appreciates the support from his/her family and the nurses need to respect this. On the contrary, nurses need to plan

the care in a way that includes the family in the care and where possible they should be actively involved in the delivery of the care.

Individualism: a paradox in the Cypriot society

Individuality is perhaps one of the most rapidly developed notions in the society of Cyprus especially when it comes to health care. People value their individuality and expect others to treat them as separate individuals with unique needs, preferences and expectations. This is one of the contradictions since Cyprus also shares many characteristics with collectivist societies.

Growing affluence and geographic mobility has spread cultural individualism. Similarly, individualism is higher among the affluent, socially and geographically mobile, more modern segments of collectivist societies. As countries like Cyprus become more prosperous, individualism rises, especially among the young. Other possible explanations of this rise of individualism come from the fact that Cyprus is becoming more and more multi-cultural and a multi-ethnic society. People from other cultures, more individualistically orientated, bring together their beliefs, cultural norms, and values which are slowly blended with the beliefs, cultural norms and the values of the Cypriots and the accession in the EU has contributed to this. Nowadays, children often are encouraged to identify personal preferences and to pursue personal goals and achievements (role models studied by them, give these silent messages). As a consequence, they begin to establish separate identities from their parents. In an individualist society, the pursuit of personal goals that conflict with family norms may be acceptable, even expected. Children's successful cultivation of separate identities leads to a degree of detachment from their families by the time they are adults. Detachment from families often establishes a similar pattern of detachment from other in-groups, such as employers, religious groups and civic organisations.

The changing expectations of patients themselves have led to demands for caring to be characterised by individuality rather than the sameness' of institutionalised routines (Kelly 1998). This growth in patient empowerment has led in a new awareness of the

unclear boundaries which exist between paternalism and caring when dealing with vulnerable patient populations (Salmon and Hall 2004; Wolff et al. 2003; Goodare 2002). In the NHIS, the notion of individuality and personalised care has been taken into consideration by the MoH and the independent specialists, so that the care provided will be tailored to the individual needs of the patient and choice will be offered to them (Polyneikis and Kalos 1992).

Nurses are morally obligated to respect the individuality and uniqueness of all those receiving nursing care (Thompson et al. 2000) and individualised care is highlighted in the various normative codes of nursing and it is considered an element in quality nursing care (Attree 2001; Waters and Easton 1999).

The importance of the notion of Health

According to Goudas and Diamantopoulos (2006) health in Antiquity was a Goddess, “*Hygeia*”, the daughter of Aesculapius and the sister of “*Panacea*” (all-cure) and “*Iaso*” (therapy). Asklepios was the Greek God of Healing, legendary son of Apollo, who is credited with introducing Greek medicine into Rome (Thompson 1962). The greatest exponent of Greek medical art was Hippocrates (460-370 B.C), by tradition seen as the “*Father of Medicine*”. His keen powers of observation being one of his most noted faculties, and the high ideals he established in the Hippocratic Oath are still used as a guidepost in modern medicine. Greek physicians were craftsmen trained as apprentices under other physicians. They canvassed their services from house to house, but this custom was later replaced by that of each family employing its own physician, as in Roman times (Thompson 1962).

From the history of Cyprus I have identified some passages from the Classical, Hellenistic and Roman eras that describe the ideas that related to health. The state of health was of great importance to the ancients as it is today, for its absence was affined with death, a phenomenon always mostly undesirable despite its naturalness. Some of these ideas can still be traced in the way people in Cyprus face health, illness and death (Pantelidou and Chatzikosti 1992). Health was (and still is) a divine gift and those who

possessed it were considered blessed by the Gods (Atsma 2007). Most humans were born healthy, and it was up to them to keep their health status by living in virtue and prudence. People prayed and made sacrifices to Gods to give them their health (Pantelidou and Chatzikosti 1992). Those that did not live this way would probably lose their health. As for the children that were unlucky enough to be born with defects, it was their parents or grandparents sins that caused them⁶⁵, a concept still popular among Cypriots nowadays. It was (and still is) a mixture between Gods' will and man's deeds that determined one's health (Goudas and Diamantopoulos 2006).

Illness and death have always been a feared idea for the Cypriots, and this fear has brought them closer to the Gods (then and now) and it became a way of living for those who valued their health and lives. Papadopoulos and Lees (2004) assert that these beliefs can influence participation in prevention and early detection activities, decisions about treatment, emotional responses and family relationships. Thus, understanding these culturally-based responses is as important to nurses as knowledge of statistical trends.

The nursing context in Cyprus

In general terms, the relationship between nursing context and patient care is nebulous, and difficult to demonstrate. It has not been the main focus of this study and findings remain tentative. However, the nursing context does appear to influence aspects of patient care, with some of these influences being clearer than others. With many aspects of the nursing context being discussed in previous chapters, in this section I will describe those aspects of nursing that may have influenced implicitly or explicitly the outcomes of this study.

The review of Cyprus ethnohistory revealed that there were not specific nursing structures for the provision of organised nursing care, at least not until the arrival of the British in 1878. However, despite the lack of organised care, the sick, the poor, and the needed were being cared for primarily by their family and at their homes (Anastasiou 2000). The role of the carer was primarily assumed by the women, an aspect which also

⁶⁵ In Greek this belief is known as “*αμαρτίες γονέων παιδεύουσι τέκνα*”

continued with the foundation of formal nursing structures in Cyprus with nursing been a profession that employed only female nurses for many years (Mitsiga 2005). What has guided nursing practice at the early phases of its history were the Christian values such as “love” and “love for your neighbour” which are described in the Bible with the parable of the Good Samaritan. These influences became more apparent with the introduction of Christianity in Cyprus during the Roman period.

British occupancy occurred at a period when the structures of the future state were developing and thereby influencing them. They organised the health care system based on the model they had used to structure the British NHS (Anastasiou 2000). In 1883 and 1890 they established the first hospitals in Cyprus (Mitsiga 2005). Prior to their occupancy, only 2 small hospitals operated on the island one of which was a hospital for leprosy (Anastasiou 2000). They brought to Cyprus the medical technology of the time, physicians, trained nurses as well as vaccines. What is important to discuss here is the structure of the wards at the time. The British brought nurses from the UK who were employed as ward managers (sisters). Cypriot women received limited training, mainly practical, by the sisters, in order to attain the role of the “assistance nurse”. The Cypriot nurses belonged to the lower class; they had no formal education or nursing training an aspect which has led the public to create a rather disappointing image of nurses (Mitsiga 2005; Anastasiou 2000). Often this prejudice can be traced in today’s friction with older patients. Patients often think that nurses are their “servants” and their job is merely to serve them. This behaviour also reflects the views that the Greek-Cypriot society holds about women and the status of women in Cyprus, since most nurses are women⁶⁶. Cypriot women from the ancient times were expected to have the role of the mother, the carer for the family, the home, the children and the husband (LCCS-Library of Congress Country Studies 1991). Therefore, patients often expect the nurses when caring for them to adopt the role of the “carer” that the Cypriot woman has in the family.

In 1945, the Cyprus School of Nursing was established and professional nursing education was introduced. The education was based on a two year programme, which was later upgraded to a three year program. Ever since the establishment of professional

⁶⁶ World Health Organisation 2007

nursing education in Cyprus, its development has been rapid reaching its peak in 2007 with the introduction of university level nursing education in the newly developed Cyprus Technology University. This has been an anticipated development by the nurses and the patients (public) bearing the fact that the nursing care is developing and becoming more specialised and demanding which calls for more educated nurses in order to assume new roles and appropriately meeting the patients' and the public's increased needs and expectations. The personal and educational development of the nurses will according to Mitsiga (2005) reinforce two important values in nursing, that of sharing and equality. The value of sharing encompasses the sharing of work, the sharing of problems, the sharing of knowledge and the sharing of social worlds that exist for nurses beyond the professional arena. Sharing underpins the development of teamwork and the idea that everyone, (nurses and patients) has a valuable perspective. Similar to "sharing" the value of equality is associated with the sharing of work, the autonomy of individual nurses, the notion of a flattened hierarchy, the principle of partnership with patients, the idea that everyone's opinion is valued, and the importance of local decision-making and conflict resolution. With the launch of university level of nursing, more opportunities are presented to the Cypriot nurses to get involved in research studies both at national and international level through collaborative projects. Through research, nursing is moving towards a more evidenced-based model, whilst the cultural characteristics of the population can be studied and understood in relation to health issues.

The image of physicians who were and still are predominantly male is better than that of nurses (Anastasiou 2000; Chresanthes 1983). Many people (mostly elder) have unquestioned trust in their physicians whose words are considered "evangelio" (bible) and therefore obeyed (Vrionidou 2006). Increasingly however, people are questioning their physician's motives and advice whilst demanding information and involvement in the decision about treatments and care (Vrionidou 2006). Another important aspect of the current status of nursing in Cyprus was the recent establishment of an independent Nursing Division⁶⁷ in the MoH contrary to the past where nursing was managed by the

⁶⁷ See appendix B – Diagram 1

Medical Division (Tapakoude 2001). This allowed professional nurses to take leadership and deal with the problems, needs and the relevant developments of nursing. Therefore, issues such as the nurses' training and development, the establishment of professional standards, quality assurance and the development of nursing professionalism in the various nursing departments are now being addressed by nurses (Tapakoude 2001). This development resulted in strengthening the perception of nursing as unique clinical expertise. This idea of nursing as having distinct areas of practice and as central to the welfare of patients has also been linked to the primacy given to psychological care by the newly independent nursing division. This view of nursing can also be recognised in the way that nurses wish to remain in clinical practice, rather than seek promotion in management, education or research.

The introduction of the independent Nursing Division came as a challenge to many long-lasting unspoken rules that dominated the nursing profession and particularly its relationships with the physicians, the patients and other healthcare professionals. These rules are the legacy left by the British when introducing the first structures in nursing. The role of the nurse as the "right hand" or "helper" of the physician was an aspect of this legacy (Anastasiou 2000). As a result nurses were "prohibited" to assume roles or perform procedures that were traditionally considered as medical. Nurses did not have the authority to inform their patients about aspects of their care and treatment, not even the medication (Anastasiou 2000). This was perceived by many patients as a weakness of the nurses to assume leading roles in their care and therefore their contribution to the care was undervalued. Some nurses tend to nourish this perception by "hiding" behind the physicians' orders. Many times when the patient challenges the authority of the nurses for a particular procedure, the easy way for the nurses is to call upon the physician's orders which the patient will not dare to challenge. This had and still is negatively influencing the nurse-patient relationship, because the nurse is perceived as a subordinate of the physician which may trigger analogous behaviour from the patient towards the nurse. Until today nursing has struggled to disengage from this long-lasting legacy, however with modest success, mainly due to nurses receiving their education and training alongside nurses and doctors from the previous generations who hold

outdated beliefs and values (Mitsiga 2005). However, the recent changes resulting in nursing becoming more independent in the clinical setting have positively influenced the relationship between the nurse, physician and the patient.

These beliefs held by the Greek-Cypriots are considered important for the purpose of this study as they work as a guide as to what the patients expect of the nurses, how they view the nurses and how they want to be cared by them.

Life-threatening illnesses as taboo issues.

The word “taboo” originates from the Polynesian islands of Tonga and means forbidden or literally “tapu: the deeply marked” (Frazer 1990). It refers to commandments and prohibitions among natural tribes which, if violated, can have dire consequences. Various actions, objects or persons can be taboo – in particular among many people this includes anything to do with illness and death. Our present day civilisation also has its taboos, which are based on moral, ethical and religious concepts. Just as social values and norms are continually changing, so do the topics around taboo change too.

Cypriots respond in their own way when it comes to illness and especially life threatening illnesses. Cancer, AIDS and other life threatening illnesses are still considered as taboos by the Cypriots. However, it is not just the life threatening nature of an illness that makes it a taboo. Chapple et al. (2004) argue that people may also feel shame associated with having a condition and fear being discriminated against on the grounds of imputed inferiority or social unacceptability. According to Sontag (cited by Chapple et al. 2004, p1470), cancer is often “felt to be obscene—in the original meaning of that word: ill-omened, abominable, and repugnant to the senses”. A society where its people find it difficult even to pronounce the word “cancer” calls for more sensitive approaches to the issue. For Cypriots it is common to avoid using the word “cancer” and instead using words such as “it” or “ekeino” or “the disease” (Papadopoulos 1999a). This particular behaviour rooted back in the old times and is based on the fear that if they enunciate the word “cancer” then the disease will come in their homes and they or some members of their family will become ill due to cancer.

Furthermore, the social stigma surrounding some cancer diagnoses, such as breast cancer, cervical cancer or AIDS-related tumours, suggests that certain patient groups may have specific care needs arising out of their increased risk of social isolation. Such isolation may stem from the socially constructed attitudes which their diagnosis has acquired (Kelly 1998). Caring in such situations may require the professionals to recognise the consequences of this isolation and to develop interventions to minimise its impact. Whilst the concept of individualised care seems to have become a somewhat ubiquitous slogan within healthcare, this need to be supported by evidence to show how the needs of those patients experiencing stigmatised illness can best be met.

Conclusion

Through this brief historic review of the people of Cyprus, the most important events or facts that influenced the way that they perceive health, illness, health services and nursing were identified.

One crucial tenet of hermeneutics is its belief that culture and history matter, and that we can only reach understanding as “historically and culturally located beings” (Rundell, cited in Crotty 1998, p91) and hence these need to be taken into consideration in every stage of the research process. However, the ethnohistory is not important only as far as it concerns the informants of the study but also for the researcher. In hermeneutic phenomenological studies the researcher is considered an inseparable part of the research who takes an active role in the study and this way influencing the decisions in relation to the research process and with informants’ perceptions form the research data.

Having knowledge on the ethnohistoric background of the country enables one to relate or interpret the study findings in the light of this important information, which often open a new perspective both for the researcher and also for the reader. This allows the researcher to go beyond the obvious and “read between the lines” or as Ricoeur would say “moving from what the text is saying to what the text means”. Moving on to the next chapter, the actions performed as part of the data collection and analysis process are

analysed in detail. Ricoeur's interpretation theory, as this has been modified to suit nursing, has been applied in order to analyse the research data and is further discussed.

PART 3

CHAPTER 5

METHODOLOGY AND METHODS FOR DATA COLLECTION AND ANALYSIS

Introduction

“Inquiry is inquiry, regardless of methodology”

(Dzurec and Abraham 1993, p2)

This chapter gives an account of the empirical phase of the research and explains and justifies the approach taken. This phase of the study involved a series of interviews with 25 patients with cancer, with 20 nurses, two focus groups with patients and a focus group which consisted of the key advocates from the cancer associations.

The primary aim of this study is to develop a theory of the quality of nursing care- *ποιοτική νοσηλευτική φροντίδα*-in cancer care departments that has the power to explain the significance of good practices, sometimes that do not occur in institutional care, and to identify and illustrate aspects of current nursing practice that will promote the quality of nursing care for patients with cancer. I am conscious that, by engaging in a pursuit of a definition of quality nursing care, I run the risk of betraying hermeneutics by slipping into the philosophical doctrine of essences. Definition, however, according to Moules (2002) is not necessarily essentialist, nor is it betrayal if we consider that definition⁶⁸ is the shape that language takes around a word. “It is only when we begin to believe that definitions are “true” that we betray hermeneutics” (Moules 2002, p4). What we betray is the idea that there can never be just one universal truth for things.

This chapter develops in the following way:

- i) It is argued that hermeneutics provides the ground of a new approach to the quality of nursing care.
- ii) The methodological decisions are explained and justified.

⁶⁸ In hermeneutics the definitions are considered as interpretations, and will be referred to as such.

iii) The process steps underlining the analytical approach are discussed.

Therefore the chapter moves from the general to the specific. At every point, the decisions taken and the strategy adopted are justified through reference to the literature of hermeneutics.

Hermeneutics: the philosophical basis for this study

This study consists of a programme of qualitative research that is based on a hermeneutical foundation. It is possible to justify the conjunction of hermeneutics and health sciences research by citing precedents.

This section of the discussion illustrates that many practical and theoretical disciplines have explored the implications of hermeneutical philosophy for their research methods. The range of these disciplines is described in order to show that this study is located within an established and growing tradition of hermeneutical research, and that the research strategy employed reflects the consensus of that tradition.

Thompson (1991) asserts that it was only after the 1970s that there has been an increasing reference to hermeneutics in the methodological literature of the health sciences. Prior to this date, the discussions of hermeneutics were most commonly found in such disciplines as continental philosophy, theology, and literary criticism. This literature discusses hermeneutics as a philosophy that redefines the scope and nature of the health sciences (Lindseth and Norberg 2004; Benner 1994; Allen and Jensen 1990). It recognises hermeneutics as a philosophy that supports an approach to health research which focuses on meaning and understanding in context, and which is therefore appropriate for this study. This methodological literature is part of a movement among practitioners and scholars in applied disciplines who are becoming dissatisfied with positivism as an adequate philosophical grounding. As a consequence of the steady growth of interest that occurred in the 1980s, hermeneutics has emerged as a philosophy whose relevance extends beyond the humanities to the practice disciplines, and even to the natural sciences themselves.

The range of disciplines whose scholars have explored the implications of hermeneutics for practice and research includes anthropology (Maranhao 1986), education (Olson, 1986), psychology (Honey 1987), clinical psychology (Silvern 1990), psychoanalysis (Harney 1978), psycho-biology (Fischer 1987), medicine (Lock 1990; Churchill 1990), social science (Hekman 1986); the philosophy of natural science (Rickman 1990; Kelly 1987); and nursing (Rather 1992, Diekelmann 1992; Allen and Jensen 1990).

Hermeneutics and Health Research: Establishing the Precedent

A considerable precedent exists for the concurrence of hermeneutics and health research. Database searching of research published shows that researchers in the disciplines of health sciences and particularly nursing have taken this approach: Finch 2004; Whitehead 2004; Lindseth and Norberg 2004; Wiklund et al. 2002; Koivisto et al. 2002; LeVasseur 2002; Walsh and Kowanko 2002; Cronin 2001; Robertson 1999; Fagerstrom et al. 1998; Drapper 1997; Walters 1995.

Empirical phase of this study Negotiating access to the research sites

Following the successful registration of the research proposal by the university, I commenced the negotiations for accessing the research sites. My previous experience with research studies in Cyprus has made me aware of the lengthy periods that are required to succeed such permissions from the MoH, so the negotiations began as soon as possible.

Due to the fact that not all the research sites are governmental organisations, discussions had to be held separately. The general manager of the MoH was fully informed about the details of the study, its aims and purposes, the intended outcomes, and the potential benefits that the study will have specifically for the patients and the nurses and more generally the cancer services. The effort was focused on persuading the manager that the research study would have positive outcomes. It was emphasised that the study is addressed to an area of care which is understudied in Cyprus and an area where

European Guidelines press for changes and particularly in quality issues⁶⁹. At the time that the negotiations were held the MoH was experiencing pressure by the cancer associations, patients with cancer and the public in relation to cancer care services, and the study was seen as a positive measure to improve things for patients with cancer. The timing to submit the proposal was opportune and I believe it facilitated its approval. The proposal was submitted to the MoH with responsibility for the Nursing Services, because apart from the patients it is also focused on the nurses working in cancer care departments.

Parallel to these negotiations, discussions were held with the BOC Oncology Centre (Bank of Cyprus Oncology Centre), a non-governmental organisation which, is managed by a board of members though some aspects of its operation are regulated directly by the MoH. A meeting with the centre's general manager was arranged during which the proposal was presented in detail. The manager was also informed that the study was reviewed and approved by the HSESC (Health Studies Ethics Sub-Committee) of the Middlesex University and the MoH⁷⁰.

Both the MoH and the BOC Oncology Centre decided to participate in the study and no restrictions were placed on me. On the contrary, both establishments offered me every possible help that would facilitate my work in relation to this study. After the permission to carry out the research study was issued I met with the participating hospitals' managers and ward managers to inform them about the study and to facilitate the process of identifying and selecting possible informants-patients and nurses- to take part in the study. This was by no means a method of coercion to force nurses or patients to participate in the study. My request of them was to simply express their support for the study, so that the nurses would be willing to freely participate.

Sampling

The hermeneutical nature of this study is reflected in the sampling decisions. Therefore, these were not taken on the basis of acquiring a representative sample but rather they

⁶⁹ Also see chapter 3

⁷⁰ See appendix D - 5

reflected the need to identify informants for interview who could discuss the meaning of the quality of nursing care and describe practices and situations which could enhance and or impair the quality of nursing care provided in cancer care departments. Sampling decisions were customised by the decision to include informants from each of the different cancer care departments that were available within the public and private hospitals. The size of the sample was also influenced by the redundancy of data, which occurred when the pool of ideas and practices described by the informants appeared to be exhausted; and finally by the fact that I wanted to include in the sample informants from a variety of age groups, educational backgrounds and of both sexes something that was achieved in the final sample.

Selecting the patients-informants

In keeping with the aims of qualitative research, the samples for this study were not selected based on the need to generalise findings but by the desire to achieve rich data about the experience of being treated for cancer. The purposive sample of 25 informants included hospitalised adults with cancer in a 16-bed department located in the south area of Cyprus (LGH), a 32-bed oncology centre located in the inland of the country (BOC Oncology Centre-Nicosia) and in a 12-bed cancer care department also located in the inland (NGH). A purposive sample is defined as informants who have specific characteristics or features (Higginbottom 2004). Purposeful sampling is used most commonly in qualitative and particularly phenomenological and hermeneutical inquiries. This method of sampling selects individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge. As Patton (2001, p169) asserts, the logic and power of purposive sampling “lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling”.

The selection of informants was made with the assistance of the hospital ward managers, who gave me access to the selected wards. Three meetings, one for each hospital, were arranged at which I explained the purpose and nature of the research study.

A number of patients were selected from each of the three departments chosen. The qualitative nature of the study allowed the number of informants selected from each department not to be analogous to the total patient population that uses their inpatient services every year. Therefore, the final sample was consisted of 10 patients from the BOC Oncology Centre, 8 from the LGH and 7 from the NGH. It was felt to be inappropriate to delegate the selection of patients to ward nursing staff who may have been reluctant to choose patients whom they considered to be confused or difficult. In principle, any patient was considered to be eligible for the study whose name appeared on the ward list. Patients were selected from the list according to certain criteria: I interviewed adult patients of both sexes (18 years of age or older) with cancer, and who required hospitalised treatment. The final criterion was the willingness of the person to be interviewed for the study. The exclusion criteria included patients that required treatment in protective isolation, newly diagnosed and terminally ill patients. I considered newly diagnosed patients, those who were diagnosed less than 6 months ago. The selection process continued until the desired number of informants was achieved. In total, twenty five patients were selected in this way. During the selection process three patients refused to take part in the study. For these patients a justification for their decision was not requested. Two focus groups with patients with cancer were held, one in Limassol, and one in Nicosia. The informants that formed the focus groups were purposively selected from those that were individually interviewed.

Selecting the nurse informants

The nurses who manage and deliver hospital cancer care influence the quality of the care provided to patients with cancer (Adams and Bond 2003). As the ward managers probably have great potential influence, I interviewed eleven of them as part of this study. The remaining nine informants were nursing officers (staff nurses). The twenty informants were selected by purposive sampling (Cohen and Manion 1989). Eligible informants were nurses from both sexes and all levels of nursing staff with at least one-year experience in cancer care departments. The working experience was set as a

selection criterion so that the informants would have enough experience caring for patients with cancer.

In order to acquire the opinions of more experienced nurses I decided that it would be better to select a larger number of informants from the cancer care department of the NGH. This department had been operating for a longer time than the other two departments included in this study. The cancer care department in the LGH began to offer inpatient facilities only two years prior to the data collection phase of this study while the BOC Oncology Centre was launched in 1998. Therefore the NGH had 10 nurses in the sample, the BOC Oncology Centre had 6 nurses and the LGH was represented with 4 nurses. In the sample, women and men were equally represented. The age groups varied from 22–55.

Selecting the key advocates

The six key advocates from the two cancer associations were interviewed in a focus group held in Limassol. The key informants were mainly members of management committees and policy makers of the cancer associations with wide experience in issues related to cancer nursing and palliative care.

Informing the patient informants

Despite the initial planning that the potential informants were to be informed in two meetings at the cities where the participating hospitals are located, this could not be effectively applied in practice. The reasons were that not all the patients could attend these meetings at one time and because some of the patients were reluctant to participate in such meetings as they did not want others to know that they had participated in such a research study. Therefore I decided to inform each patient individually. This allowed the patient to ask questions and clarifications regarding the study easier than he could have done in a meeting with 5-10 patients. The small number of the sample allowed this procedure to be carried out within the planned time limits.

The general feeling I got from the process of informing and recruiting the potential informants was that the patients were excited about this study and agreed that such

studies are necessary and beneficial for them, and that more studies should be encouraged. The positive feeling for the study can be acknowledged by the small number of individuals that refused to participate in the study. All lay informants (patients and non-patients) gave their informed consent in writing⁷¹.

Informing the nurse informants and key advocates

The nurses that expressed their interest in participating in the study were informed in 3 meetings set up in the three departments. Once the necessary explanations were given to them, including what is expected of them, they were all asked to sign the consent form. Their legal rights were emphasised to them and especially their right to withdraw at any stage of the research process with no questions asked. As in the case of the patients, it was not hard to complete the sample because nurses gladly participated in the study. They saw this study as their opportunity to have their voices heard. The small number of the key advocates allowed me to individually inform them about the various aspects of the study.

Data collection methods

The narratives

The narrative approach is suggested by hermeneutic phenomenology for exploring the lived experiences. An issue that I kept in mind was the phrase “*Man is Language*” as both Ricoeur and Heidegger were fond of saying. Language as “institution” is already a social phenomenon. Therefore, according to Ihde (2004) even though seemingly distant, “the questions of the structure or logic of language retain subterraneously linked to questions of sociality and human historicity” (px). The review of the ethnohistory of Cyprus revealed important information that was considered in the narratives. Furthermore, through the literature review and the review of the NHIS certain aspects of quality emerged which I wanted to explore through the study, and therefore certain stem questions were held in mind. The questions were formed based on the literature review on quality, the research aims and research questions of this study.

⁷¹ See appendix-Informants information sheet and consent form

Translation process

Once I agreed with my supervisors which stem questions would meet the study aims, I began the translation process to the target language which was Greek. I and my supervisors agreed on the process that was to be followed to achieve valid questions in the target language (*construct validity*) by translating the meanings of the questions of one particular language into another as Ricoeur (2004) asserts. During the first step I translated the questions into Greek. These were also translated by the first supervisor (Director of Studies) who also has Greek as her native language. Prior to the translation process the two researchers were not aware of each other's translated version, thus implementing a parallel blind translation process. The parallel blind translation is a technique in which two translators independently prepare versions of the draft target language instrument (Behling and Kenneth 2000). They then meet to compare their versions and to resolve any differences. In this case the two translated versions did not differ in relation to the meaning of the questions. Their differences were minor and consisted more of the choice of words rather than the meaning of the questions. The question that arises here is "why this technique and not another?" The answer comes from Behling and Kenneth (2000) who assert that parallel blind technique has two advantages: speed, an element which is labelled "*practicality*", and research control, an element which is labelled "*source language transparency*". The translation process is faster than conventional translation/back translation because the two translators work in parallel rather than in sequence. Also checking the two translations against one another provides an element of security.

In the history of hermeneutics the problem of translation has troubled philosophers over the years. As early as biblical exegesis and the work of Schleiermacher⁷² and other subsequent philosophers, translation has played a central role. Similarly, in the philosophy of Ricoeur the issue of translation does not raise any conflicts or threats to the text and is considered a natural act of language (Ricoeur 2004). Translation has been a central theme of Ricoeur's philosophy according to Kearney (2006). Well before Ricoeur thematised the subject, the act of translation was something which he actually

⁷² Schleiermacher's theory of translation

performed in his philosophical practice. For Ricoeur there are two routes by which translations is understood; that of the specific and the general sense. In the specific sense, which I have employed here, it signals the work of translating the meanings of one language into another. In the more generic sense, it indicates the everyday act of speaking as a way not only of translating oneself to oneself but also more explicitly of translating oneself to others (Kearney 2006).

Pilot study

Despite the fact that in the research proposal a pilot study was not planned, one was considered essential to find out whether the informants were able to understand what was expected of them and provide experiences relevant to this study's aims. A small random sample of patients (3) was interviewed. The following changes were suggested by the pilot:

An issue that received serious consideration during the development of the opening questions and the stem questions and the interview process was the type of language that was about to be used. This is important, considering that the methodological approach of this study is hermeneutic phenomenology which is focused on textual interpretation, and therefore the texts hold a central role for the interpretation and understanding⁷³. An example of how the issue of language was considered in the process is provided here. The aim of this study is to find out elements that negatively or positively influence the quality of the nursing care by maintaining a humanistic approach to the issue rather than an audit approach. Therefore, words indicating measurement such as "rate" and "achieve" were avoided in the narratives and replaced with alternative words that maintained the humanistic approach. Based on the pilot interviews I have also considered the possibility to replace the term "quality nursing care" with "menu for a model of good practice" as it seemed that patients understood this term better. However, the term "quality nursing care" was retained and used with the term "menu for a model of good practice" as an explanation. Furthermore, the patients' avoidance of the word "cancer" in their narratives revealed some of the cultural influences discussed in chapter

⁷³ Also see chapter 2

4, disclosing negative feelings for the patient. Therefore, the phrase “your illness” was preferred instead of the word “cancer”. Additionally, I made arrangements with the hospitals’ psychiatric department, so that in the event that any emotional disturbances should occur due to the interviews or focus groups, support could be offered to patients.

Data collection in hermeneutic studies

In gathering their data, what hermeneutically oriented nurse researchers are trying to ensure is that the subjective character of the data is left intact and untainted. It is all too easy for researchers to structure the data-gathering process in ways that virtually guarantee them the data they are after. Most investigators that lay claim to a “hermeneutical approach” set out very deliberately to avoid this. For example, they pay attention to the way in which they conduct their interviews. The interview is intended to yield a conversation, not a question/answer session. Not only is the interview open-ended in this sense, but it also tends to use open-ended questions. Several researchers are cautious about asking questions at all, adopting non-directive techniques such as active listening, reflective silences, repetition of statements and refocusing responses. Many emphasise that, beyond the opening question or two, further questions are asked only to gain clarification or encourage the respondent to keep talking.

The opening question or questions are designed to elicit descriptions of subjective experience. A manner of proceeding that appears very appropriate to a number of the authors, including myself, is to ask the respondents to describe a situation or an experience:

- Describe an incident when you thought that, this was quality nursing care.

When asked to describe a situation in this way, the informants may be invited specifically to share thoughts, perceptions, and feelings about the situation. The informants may be asked to describe these ideas or sentiments until they have no more to say about the situation or have finished or exhausted their descriptions of the

phenomenon. The researchers obviously consider thoughts, perceptions and feelings to be very much what hermeneutics is about.

In hermeneutics, the primary source of knowledge is everyday practical activity. It calls for the ability to undertake engaged reasoning in particular situations and particular texts. In this sense it is analogous to clinical reasoning. Human behaviour as Ricoeur (1976) asserts becomes a text-analogue⁷⁴ that is studied and interpreted in order to discover the hidden or obscured meaning. This meaning is hidden because it is so pervasive and taken for granted that it goes unnoticed. The interpretation of indirect or tacit meaning invites us to think more, not to abandon speculative thought altogether. And nowhere was this more evident than in the challenge posed by symbolic meaning. Kearney (2006) asserts that by symbols Ricoeur understood all expressions of double meaning wherein a primary meaning referred beyond itself to a second meaning which is never given immediately. This “surplus meaning” provokes interpretation (Ricoeur, 1976).

The data for the text-analogues came from narratives, and focus groups. Narratives represent the most basic way to gain understanding of our own experiences through narrating them and listening to others' narratives. Kvale (1996) suggests that the qualitative interview is a particularly suitable method of data collection for hermeneutical research, because it implies a hermeneutical mode of understanding in which people are able to describe their world, their opinions and their acts, in their own words, and subjects can organise their own description, emphasising what they themselves find important. Ricoeur in his work “*Time and Narrative*” (1984b) emphasises that we have a pre-understanding of life, which finds expression in the shape of stories. Lindseth and Norberg (2004, p.151) assert that “We organise our experiences so that they answer questions like: ‘what’, ‘why’, ‘who’, ‘how’, ‘with whom’, ‘to whom’ and ‘for whom’”. Talking in terms of the hermeneutic circle, a story is a whole, which gives meaning to particular events, which give meaning to the whole story. It is through the circular movement which occurs as part of the hermeneutic circle between

⁷⁴ An example of a text-analogue is an organisation, which the researcher comes to understand through oral or written text.

the whole and the parts that understanding becomes possible. Palmer (1969) explains that the whole receives its definition from the parts, and, reciprocally, the parts can only be understood in reference to a whole. A story constitutes dialectic between the past, the present and the future (Ricoeur 1995). Similarly, Lindseth and Norberg (2004, p150) assert that “To retell an event means to bring the past into the present in order to shape the future. A story enables the listeners/readers to see their world in new ways”.

Focus groups were used in addition to narratives to achieve breadth rather than depth of information. These were used on the basis of the fact that this could stimulate a joint description of the phenomenon as the interviewees could get ideas from others in the group. By using the dynamics of groups, I wanted to provide an opportunity for the informants to “consider their own experiences in the context of others experiences, and possibly be stimulated to further elaborate on these together” (Patton 2002, p389-390). The focus groups also served another purpose. I constructed the focus groups sessions in such a way that opposing perspectives could be discussed, something that allowed the manifestation of data. The rationale for this lies in the work of Ricoeur (1974) “*The conflict of Interpretations*”. Through the opposing ideas expressed in the narratives, by the informants, I wanted to explore whether the conflict of interpretations that emerged was rooted in certain beliefs, values or expectations that the informants held or it was a matter of different interpretations.

These approaches encouraged the informants to reflect on, rather than merely to recall anecdotal experiences to me. Tapping into such interpersonal communication is important because this highlights cultural values or group norms. Kitzinger (1995, p300) asserts that “through analysing the operation of humour, consensus, and dissent and examining different types of narrative used within the group, the researcher can identify shared and common knowledge”. This makes a focus group particularly sensitive to cultural values, a reason why it was preferred from other qualitative approaches. These approaches are not a free conversation, but neither do they follow a highly structured list of pre-determined questions. The interviewer’s task is to structure the encounter in such a way that the informant can give a full and clear account of his or her ideas. Benner

(1994) asserts that that the researcher's aim in the interview is to "seek engagement in the informant's world and through informant observation and interview sets up a friendly dialogue where understanding can occur" (p7). During a narrative interview the researcher who acts like an interviewer encourages the informant to freely speak about his/her lived experience of the topic chosen. The aim is that the resulting narrative should, as far as possible, be the narrator's own (Lindseth and Norberg 2004).

This allowed me and the informants to move back and forth between topics in order to elaborate upon meanings and to consider possible relationships between events whilst maintaining a firm focus upon the fundamental research question. This approach was considered consistent with hermeneutic technique since it recognised the contribution of both informant and researcher to the generation of research data. Interviews and focus groups were tape recorded in preference to asking for written accounts since it is claimed that most people are able to talk with ease, eloquence and with less reserve than they are able to if they commit their thoughts to paper (Van Maanen 1997). Personal interaction with the informants offered me the ability to clarify indistinct areas of the interview and most importantly it allowed me to challenge the taken-for-granted perspectives of the informants. Personal contact also allowed me to experience more than words such as the ambience, the feelings of the informants, the context and the paralinguistic. All of these elements are of primary importance because as Ricoeur (1981) asserts our everyday lived experience is so taken for granted as going unnoticed. It is often through its breakdown that the researcher achieves flashes of insight into the lived world, although it is important to note that the taken-for-granted, everyday lived world can never be made completely explicit.

Interview technique

Ricoeur (1976) argues that the presuppositions of the researcher together with the perspectives and views of the informant together form the final result of the interpretation process. Informed by this idea of Ricoeur, it was decided that data collection process could not be shared with any research assistants. Therefore, both the narratives and the focus groups were lead by me.

Interviewing for hermeneutics required training and critical reflection on my part. For example, in reading the research interview, I critically evaluated my own avoidance, silence or inability to follow up on, or hear certain concerns and meanings. A critique by other researchers could help one identify blind spots and areas of avoidance. The interviews were read by the two supervisors and this way we were able to identify these blind spots and areas of avoidance. Moreover, the multiple interviews gave me the chance to clarify what was left unexamined in the previous interviews.

Narratives of 45 minutes duration were agreed as a reasonable period, although the need to retain some flexibility was recognised. Interviews were recorded on a small portable tape recorder for later transcription. On one occasion the informant refused to have our conversation recorded, so I took detailed notes during the narrative.

The quality of the narrative may be impaired if insufficient attention is paid to the possibility of reactivity. Reactivity occurs when the interviewer imposes his/her own perceptions on the informant through the form and content of his/her questions. This possibility clearly existed in the present case, as I was experienced in the clinical care of patients with cancer and held certain views. The following aspects of the interpersonal relationship between interviewer and informant also add to the danger of reactivity: i) the role of the interviewer is often more clearly defined than that of the informant. Informants may have very little idea of what is expected of them, and may lack the necessary skills to express complex ideas in a verbal form. Informants who are unfamiliar with their role may adopt a subordinate attitude in the face of interviewer "expertise", and express what they imagine to be a socially acceptable response, taking cues from the interviewer if these are available. ii) Research has shown that many people enjoy the experience of being interviewed and may try to reward the interviewer, once again by giving acceptable answers (Morse, 1991; Catanzaro and Woods, 1987). iii) The exchange of information might be influenced by the respective social status of interviewer and informant (Robson, 2001). In this particular study, it was possible that the responses given by nurses might be influenced by their knowledge that the research study had been authorised by the MoH. It was also possible that the patients, knowing

that I was a nurse, might have avoided criticising the care that they had received. With the danger of reactivity in mind, the goal of the interview was to lead the interviewee towards the focus of the research but to avoid leading him/her in the direction of expressing specific meanings which may have reflected my views and preunderstandings.

Interviews with patients

At the interview, some patients had difficulty in talking about the quality of nursing care. Part of this difficulty appeared to be related to their unfamiliarity with the role of interviewee: they simply did not understand what they were being asked to do. This was due to the fact that many of them were being interviewed for the first time in their lives. My response to this problem was to abandon the rather formal term “interview” and to ask the informants if I could have a chat (“*kouventa*”) with them. I also took care to structure the interaction as a social encounter. I would sit next to the person, making sure that good eye contact and occasional physical contact were possible. Sometimes I had a cup of tea or coffee with them. The interviews took place in the rooms of the patients (i.e. single rooms) and where this was not possible, the day room was used. In both cases measures were taken to ensure privacy, good air condition and quietness. The interviews were arranged with the assistance of the ward manager so that the interview process was not interrupted.

Some of the interviews with the patients included prolonged diversions into areas only tangentially related to the focus of the study. I did not interrupt these, believing that they reinforced the social nature of the interview and brought a useful sense of informality to the encounter. However, through tactful comments I tried to reinstate the focus of the interview.

As was earlier discussed, the interview was not structured according to a fixed list of questions, however certain “stem questions” were held in mind:

- What's the first thing that comes to your mind when you think of "quality nursing care"?
- Can you give me an example of nursing care that you received or witnessed others receiving such as a family member, friend or a neighbour when you thought "this is good nursing care"?

These questions were used to get the interview started, whilst retaining the focus on the quality of nursing care. The subsequent strategy was to respond to the issues contained within the informant's answer to these opening questions, and to explore them at greater depth. The following example of an opening question is taken from the interview with Mr. Petros⁷⁵: Researcher: The topic is the quality of nursing care. Can you tell me what the term means to you...? There is no such thing as a wrong answer.... I just want to know what you think.

As each interview developed, I employed the techniques of focusing, clarifying, reflecting and summarising that are described in the context of the helping interview by Egan (1986) and Connor et al. (1984).

Focusing and Clarifying

After the informants had made an initial statement, I focused on the issues that they had raised and asked them to clarify what they had said. Clarification might involve asking the informant to define a term that they had used, or give an explanation for what they had said. The following example of this process is taken from the interview with Mr. Petros: Patient: [...] the nurses need to find the balance in order to find quality. Researcher: What "balance" are you referring to Mr. Petros?

Reflecting

Minimal responses were used to encourage the informant to continue, and I reflected back on the content of what had been said. The following example is taken from the same interview: Researcher: During your stay in the department what were the most

⁷⁵ Pseudonyms have been used to protect informant's identity

important needs that you expected nurses to meet? Patient: I must say that I have plenty of needs for which I expect the nurses to assist me with. R: And what are those needs Mr. Petros? P: Basically, I need help when I move around because I feel weak and I am scared to move by myself. Because of this difficulty I can not even...can not even go to the toilet by myself and or take a shower. It's natural because of these difficulties that I expect nurses to help me, when my relatives are not here. Unfortunately, I need help when I take my meals. As you can realise as far as it concerns my self support needs, I am almost dependant on others, my relatives and the nurses [...]. R: Therefore, would you say that quality nursing care is the satisfaction of these needs? P: Yes... of course quality nursing care is related to the satisfaction of my needs and the patients' needs in general...of course for this [term] is also essential what I have said earlier about the availability of beds and the various managerial issues...all together consist of the quality nursing care and each element is equally important...The nurses need to find the balance in order to find quality. R: What balance are you referring to? P: Health services and especially nurses need to realise that for the patients' care is not the only important thing. Patients during their journey through the cancer experience should not worry about finding a bed to receive their treatment or whether there will be a nurse available to answer the bell when they need her. They should be left free of any other thoughts to deal with their medical problem. R: That is a very interesting perspective Mr. Petros. P: I think that this is an opinion that many patients share, especially in the last year when so many problems for patients with cancer have immerged. R: Yes I have seen the protests and the hunger strike outside the presidential residence. P: As you see these reactions have been the result of the many problems we the patients have to deal with.

Summarising

Benner (1994, p7) argues that the interviewer can not avoid influencing the conversation, and suggests that his/her goal should be to make the communicative dialogue mutual, comfortable, and focused on understanding the informant's meanings. To this end, questions of clarification and participation should be phrased so that the informant can confirm the informant's meanings.

Kvale (1985) recognises that the process of interpretation begins during the interview itself, as the interviewer interprets the meaning of what the research informant says, and “sends” this interpreted meaning back to check its validity. The interviewee then has the option of saying “I did not mean that”, or “that was precisely what I meant”. Consequently, I summarised what the informant had said and ask them to check the accuracy of my understanding. Here, the informant (Mr. Marie) was talking about the meaning of quality of nursing care:

Researcher: Can you give me an example of nursing care that you received or witnessed others receiving (such as a family member, friend or a neighbour) when you thought “this is good nursing care”. Patient: There are many incidents where the behaviour of the nurses is characterised by politeness and professionalism... the majority of the nurses have a fine approach towards the patient that makes them feel security and emotional support, something that is very important for the patient [...]. R: Based on your example, what would you say is “Quality Nursing Care”? P: I would say that it’s a combination of things that includes the availability of beds as I have mentioned earlier, the good staffing levels, the accessibility to the appropriate resources for the provision of the care, the good state of the facilities and last but not least the staff’s fine behaviour. R: Therefore you believe that for quality nursing care all the patient’s needs should be met even those that the patient does not directly ask for help? P: Precisely this is what I mean. Especially for those that bring the patient in a difficult spot to ask for the nurses’ help. As I have said earlier everything has its importance, but when I am in a bad emotional state I need some sort of support, an assurance that everything will be fine and definitely I do not want the nurse to avoid me.

Conducting the focus groups with patients

As soon as the data collection was completed through the interviews with the patients, the data were analysed implementing a modified version of Ricoeur’s Interpreting Theory. The interpretation of the data provided the main themes that I wanted to explore through the focus groups with the patients. The focus groups were conducted in Nicosia

(including 7 informants from the BOC Oncology Centre and the NGH) and in Limassol (including 8 informants from the LGH). Informants for the focus group were recruited through purposive sampling. The analysis of the focus groups data was performed with the same interpretation method as with the interviews. The findings provided the themes that I went to explore through the focus group with the key advocates.

Conducting the campaigning focus group with the key advocates⁷⁶

The next step included the collection of data from the key advocates through a focus group session. The informants for this session were identified and selected purposively based on their experience in advocating for patients with cancer, their involvement in policy making and their role as an advocator for the MoH in relation to issues pertaining cancer.

Six key advocates from the cancer associations were included in the study. A mutually agreed setting was used to conduct the focus group session. The same principles implemented for the patient focus groups were applied for this session as well.

Through the focus group the key advocates' perspectives and their response to patients' views in relation to quality nursing care were explored. The processes of data transcription and data analysis were the same as the ones used for the patients' interviews and focus groups.

Interviews with nurses

Following, the data collection and analyses of the patients and key advocates, the data was collected from the nurses through the individual interviews. The same procedure as used for the patients' interview schedule was implemented in order to develop valid stem questions. The data transcription and analysis methods were the same used for patient and key advocate data.

⁷⁶ Demographic data are not presented for this group of informants as the presentation of their individual details would threaten their anonymity and the confidentiality of their opinions.

Nurses who had been chosen to participate in the study were given an information sheet⁷⁷ outlining the nature of the study and explaining the contribution that I wanted them to make. In a subsequent telephone call or a personal visit, a date was fixed for the interview, and the informant was asked to suggest a place where the interview could be conducted without interruption. Most interviews took place in an office off the main ward area. Each interview began with another explanation of the research study.

Honey (1987) asserts that there is an intrinsic relationship between hermeneutics and the research interview. She states that both hermeneutics and the interview are driven by the interplay between “belief” and “scepticism”. Whilst, hermeneutics attempts to uncover or interpret meanings that are presented in the form of a mask. Hermeneutics according to Thompson (1981) aim at the restoration of meaning, which is “animated by faith, by a willingness to listen, and is characterised by a respect for the symbol” (p6). This tension between the “hermeneutics of faith and the hermeneutics of suspicion” (Thompson, 1991) is apparent during the interview process. However, according to Simms (2004) Ricoeur is not a philosopher like others. What sets him apart is the fact that he is a philosopher of faith rather than a philosopher of suspicion. Ricoeur has faith in the language or discourse in which thinking is expressed. He sees it as his mission to draw out the hidden intentions behind written works, not to expose works as deceptive.

Thompson (1981) argues that this is achieved during the interview process, where the researcher’s willingness to let the informants speak is complemented by strategies whose goal is to expose contradictions and uncover deeper levels of meaning. This is also apparent during the analytical process, where the intention to present a clear account of the informant’s views, is matched by an attempt to discover the assumptions upon which those views rest, and to highlight the conflict that sometimes exists between the rhetoric and the reality of nursing practice. The strategies of focusing, reflecting, clarifying and summarising were also used with the nurses’ interviews.

⁷⁷ See appendix-Nurses’ Information Sheet

Personal diary as a source of data

A further source of data was derived from my research journal. Personal reflections on the literature and reflections upon conversations were either documented in a notebook or committed to tape along with other experiences of professional or methodological significance. This process is considered to be a valuable way to establish rigour and reflexivity in qualitative research (Koch 2004; Koch and Harrington 1998). This position is informed by Gadamer's philosophical hermeneutics which does not show us what to do, but asks us the question what is going on while researching, and by Ricoeur's hermeneutic phenomenology who recognises the influence of the researcher on the conduct and presentation of a study (Ihde 1971). Monitoring "what is going on" according to Koch and Harrington (1998) requires that a reflective journal be maintained throughout the research process. As a researcher I brought to the research product, data gathered from a range of literature, a positioning of this literature, a positioning of me and my social-political and cultural contexts. Reflective research is characterised by ongoing self-critique and self-appraisal and that the research product can be given shape by the politics of location and positioning (Nightingale and Cromby 1999). This process was ongoing from the very first day of my study. After a conversational interview, my responses, thoughts, associations, what I was feeling, what I thought the other person was feeling, all were recorded in the diary, all were ongoing. My observations and my reflective responses to them were recorded. This is my hermeneutical journal and situates me in the life-world of my study.

When I embarked on description and interpretation, the material in this journal, most likely reflected a greatly enlarged view of the experience and a greatly changed me, as far as perspective and understanding are concerned. I believe that I have enlarged my perspective in depth and breadth and have become much more sensitive and alerted to the taken-for-granted of individual people and experiences. In my hermeneutical journal, beyond description I tried to incorporate the meaning to me of "what is going on" and the meaning of the various experiences that I had in the course of this study. To illustrate

these concepts examples from my journal are set out below, under the headings of “my lived experiences” and “pre-understandings”.

My Lived Experiences

During the data collection I explored my experiences, noting down the nature of interactions. The main issues that arose during interviews were: maintaining a non-therapeutic relationship, ensuring confidentiality, and not intervening or influencing the responses from the informants.

During the interviews I was aware of my duty to maintain the confidentiality of informants. Sometimes, quite innocent comments could have betrayed this, for instance an informant saying “I do not know if the nurses have told you about this” or “Do you agree with these comments”. It would have been easy to reveal important information simply by a nod of the head.

In seeking information or assurances about the nature of their own experience, informants commonly asked whether I agreed with them, whether it was “normal” or asked about the findings of the study so far. I felt that the informants needed a degree of reciprocity and acknowledged that feedback was vital in this. However, I discussed with them the findings very broadly, without reference to individuals in order to avoid influences and preconceptions on the issue of investigation.

During the interviews, some informants asked for advice on issues which pertained to their illness. I was aware that I should not be involved in a therapeutic relationship with informants and always ensured that boundaries were respected, reminding informants, when necessary, that I could not offer advice on these issues. I informed them about the research evidence available but stressed that this was an area to be discussed with their specialist. In this way, I prevented my role as researcher from fusing with my experience as a professional nurse.

My pre-understandings

My historical, cultural, personal and professional background were acknowledged and noted in the journal. I recorded the ways in which my socialisation into nursing helped me to negotiate access to potential informants. Familiarity with medical terminology allowed me to follow people's accounts of medical tests and procedures undertaken. Following the first interviews, I noted down my reaction to the influence of the family members on the decisions pertaining to the patient:

"[...] I entered the room in order to commence the interview with the patient...his son was in the room and when I kindly ask for some privacy he refused to leave the room...he comment that he "had" to know the context of the interview and being present during the whole process"

This entry might at first glance have little to no importance to a researcher coming from a collective culture than to a researcher coming from a more individualised culture. However, as a Cypriot studying Cypriots I knew that this behaviour is deeply inherent in the cultural beliefs and attitudes of the people of Cyprus and thus considered a natural reaction⁷⁸. Pre-knowledge of such rudiments had been an advantage for me during the research process.

Record of events in relation to health and cancer in Cyprus

Additionally to my hermeneutical journal, I was keeping another kind of record. Contrary to the personal diary where the entries were my personal views, in this record the entries were taken from media and Ministry of Health reports. My decision to keep a track of these events was based on the fact that people do not live in a social vacuum and external events tend to have an impact on their perceptions and in some cases on their lives. The events were recorded from the beginning of my studies and continued until all data were collected from the informants. Some of these events are presented below in order to help the reader to understand their influence in the study.

⁷⁸ See also chapter 4- Ethnohistory

These external events had a possible influence on my own interpretation of the data as well as on the way the informants responded to the interview questions therefore, having a twofold effect. The way by which these events influenced the informants' responses, became apparent through the choice of examples or their choice of issues they utilised in order to justify their perceptions of what constitutes quality nursing care. Therefore, the events that I had recorded during the collection of the data had also been utilised by the informants in order to give positive or negative examples of nursing practice. Furthermore, patients that were actively involved in some of these events appeared more passionate in expressing what has gone bad with their care and what needs to be changed in order to receive quality nursing care. A characteristic example was the protests and hunger strike of patients with cancer outside the presidential residence complaining about the lack of sufficient cancer services in the public sector and demanding for more resources to be allocated to this field.

Similarly, to the patients and advocates, certain external events were found to have a possible influence to the way the nurse-informants interpreted the notion of quality nursing care and in general how they responded to some of the interview questions. Recorded events such as the decision of the Ministry of Health to reduce funding for specialisation courses or lifelong learning programmes were reflected in the interpretation of the data and findings of this study. Therefore, it was shown from the findings that nurses acknowledged their limited training as the main source of many problems they dealt with when caring for patients with cancer and their families. Their difficulty in addressing the spiritual needs of the patient and in engaging in such discussions about the real meaning of life and death was also rooted in their lack of appropriate education and training as a result of the Ministry's policy to restrain the expenses.

Interpretation (Data Analysis)

“There are no facts, only interpretations....”

(Nietzsche 1886)

“Interpreting a text means moving beyond understanding what it says to understanding what it talks about”

(Ricoeur 1976, p88)

Creating the text for analysis

The research data may include many different kinds of texts. For the purposes of this study I described interview and focus group texts that were constructed in interaction between me and the patients, the nurses or the key advocates. It is important for an interview to occur in a shared speech context, where both parties share an understanding of the interview circumstances. The interview allows the researcher to ask the informant for clarifications in relation to what he/she has said when it is difficult to understand. Klemm (1983) asserts that the speaking as an event and its meaning come close to each other. Contrary, the “event of writing becomes separated from the meaning. The text becomes autonomous and open to anyone who can read” (Lindseth and Norberg 2004, p150). This assertion seems to be informed by Ricoeur’s idea of objectifying the text; that is his attempt to remove the authorial intent⁷⁹. Methodologically, objectification of the text allows researchers to move beyond the notion that only one understanding is meaningful or correct; that of the research informant. This offers the researcher “textual plurality⁸⁰ and multiplicity⁸¹”.

A tape-recorded and transcribed interview text lies closer to speech than to writing, especially if the interviewer herself/himself interprets it. It is fixated speech. The interviewee is the main author of the text and the interviewer is a co-author who has taken part in a more or less dominating way. In order to guarantee that the informant’s voice is heard in the interview text and focus group text it is essential that the informant feels free to relate his/her lived experience (Lindseth and Norberg 2004).

⁷⁹ Also see chapter 2

⁸⁰ That pre-understandings lead interpreters to interpret the same text faithfully yet differently.

⁸¹ That texts have many meanings

Following the interviews with the patients I began the transcribing and analysis process. The interviews were transcribed verbatim (in Greek) and pauses were marked by empty intervals in the text. Nonverbal and paralingual communications that seem relevant were also marked in the text (e.g. cry for about 2 minutes). The transcribed text was compared with the tape recording and adjusted if necessary. When all the interviews were transcribed and compared with the recording, they were printed and bound together to form the data source (written text) of this study.

Interpreting the text in a hermeneutical way

The analysis of the interviews was done by using a qualitative method appropriate to the hermeneutics approach of Ricoeur's interpretation theory as modified by Lindseth and Norberg (2004). Interpretive frameworks within hermeneutic phenomenology are used to search out the relationships and meanings that knowledge and context have for each other (Lincoln and Guba 1985). Increasingly, published nursing research is grounded in the philosophical theory of hermeneutics and several authors have discussed the philosophical underpinnings of this particular research approach, offering clarity and direction for others (Todres and Wheeler 2001; Geanellos 2000). A hermeneutic phenomenological approach is essentially a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomena appearing in text or written word.

Allen and Jensen (1990, p241) emphasise that "the value of knowledge in nursing is, in part, determined by its relevance to and significance for an understanding of the human experience. In order to obtain that understanding, nursing requires modes of inquiry that offer the freedom to explore the richness of this experience". Hermeneutics offer according to Allen and Jensen (1990) such a mode of inquiry. "With this interpretive strategy, a means is provided for arriving at a deeper understanding of human existence through attention to the nature of language and meaning" (p241).

The multidimensional structure of the meaning of the phenomenon is approached in terms of thematic formulation, which, in phenomenological terms, portrays experiential structures, rather than conceptual formulations (Van Maanen 1997). Gadamer (1975) elaborated by noting that hermeneutics bridges the gap between what is familiar in our worlds and what is unfamiliar: "Its field of application is comprised of all those situations in which we encounter meanings that are not immediately understandable but require interpretive effort" (pxii). As in all research, congruence between the philosophical foundations of the study and the methodological processes of the research are critical.

Ricoeur's interpretive approach is one way in which nurse researchers can apply hermeneutic philosophy to a qualitative investigation. Ricoeur as cited by Geanellos (2000) described the interpretive process as "a series of analytic steps and acknowledged the interrelationship between epistemology (interpretation) and ontology (interpreter)" (p112). Analysis is essentially the hermeneutic circle, which proceeds from a naïve understanding to an explicit understanding that emerges from explanation of data interpretation. Ricoeur (1981) placed emphasis on language, and he asserts that language and history supply the shared sphere in the hermeneutic circle. These elements of Ricoeur's philosophy of interpretation are important and need to be kept in mind as this study's data analysis process is discussed in the following paragraphs.

Interpreting a text means according to Lindseth and Norberg (2004) to enter the hermeneutical circle. Ricoeur's theory of interpretation gives the researcher means to deal with the meaning of a text, such as interview-transcripts, in a way that makes appropriation of new understandings possible. The advantage with this method of working is that there is a dialectic movement between understanding (a nonmethodic pole) and explanation (a methodic pole). Using Ricoeur's interpretation theory the way into this circle was opened by moving through three methodological steps described below (Ricoeur 1976). Wiklund et al. (2002), assert that Ricoeur's effort to fully remain in the world of the text is problematic. They explain that "as nursing researchers we are also concerned about the meaning that an event has for the person telling us about it" (p117). The process of distanciation therefore is not sufficient to appropriate the

meaning of the text. The outer context⁸² of the narrative is as important as the text in order to attain a deeper understanding of the phenomena under study. I share the opinion expressed here by Wiklund et al. (2002), and the reason for doing so lies in the fact that this study aims at improving the quality of the nursing care provided in the clinical settings. This aim materialises the movement from Ricoeur's world of the text to the clinical context. Speaking in terms of this study, for the patients and advocates, it is important to express the ways that the care provided in the clinical setting can be improved and for nurses, it is important to acknowledge the ways that they can provide better care. Here lies the rationale for choosing the approach introduced and developed at the University of Tromsø (Norway) and Umeå University (Sweden) and has extensively been used in nursing studies such as Sorlie et al. (2005; 2004), Uden et al. (1995), Lindseth et al. (1994), Soderberg and Norberg (1993) and Nordam et al. (2003). These researchers employed the Ricoeur's hermeneutic approach but modified in some aspects. The method of interpretation proceeds through three phases, "which constitute a dialectical movement between the whole and the parts of the text and between understanding and explanation" (Lindseth and Norberg 2004, p149). Therefore, the authors suggest that the interpretation process take its point of departure in Ricoeur's theory of interpretation and that the first phases are the *naïve interpretation* followed by the *structural analysis*. In the final phase the text is again read as a whole, the naïve understanding and the themes are reflected on in relation to the literature and a *comprehensive understanding* is formulated.

Firstly, during the naïve reading, the researcher reads the text as a whole to become familiar with the text and begins to formulate thoughts about its meaning for further analysis. The naïve interpretation is a preliminary interpretation of the whole. Lindholm et al. (1999) in a study on nursing management note that during this particular component of data analysis they "read all the interviews individually to gain a sense of the whole text" (p103). Their impressions of the text were then documented and discussed. In terms of this study in order to accomplish this task it was necessary for me to be open enough to allow the text to speak to me. This resulted in a first, spontaneous

⁸² I.e. the informant's meaning and how the narrative could be understood in relation to the clinical context.

interpretation and an examination of the influence of my pre-understandings. It was accomplished by reading the narratives and making an interpretation based on my assumptions and what I apprehended the text was about. This interpretation is not static or linear, but rather, it is dynamic and circular, that is, it is not formulated once and for all but is developed during the course of the structural analysis (Soderberg and Norberg 1993).

Structural analysis follows as the second step and involves identifying patterns of meaningful connection. This step is often referred to as an interpretive reading. Structural analysis is employed to discard or validate these first guesses at meanings according to Soderberg and Norberg (1993). To illustrate, Lindholm et al. (1999) noted that the researchers met to compare and discuss the texts. They describe this step in the following manner:

“The text was divided into meaning units, which were transformed with the contents intact. Arising from every transformed meaning unit a number of labels were created, to discover common themes. During the analysis there was continuous movement between the whole and the parts of the text” (p103).

The structural analysis is directed towards the structure of the text, and towards establishing whether the structure invalidates or validates the preliminary interpretations of the whole. Structural analysis is according to Ricoeur (1976) “the methodical instance of interpretation”. There are several kinds of structural analysis such as thematic analysis, search for narrative structures, and search for deep structures in the form of metaphors. Here I describe thematic analysis, i.e. a way of seeking to identify and formulate themes. A theme is according to Lindseth and Norberg (2004) “a thread of meaning that penetrates text parts, either all or just a few. It is seen as conveying an essential meaning of lived experience” (p151). In order to capture this meaning of lived experience I needed not to formulate the themes as abstract concepts, but rather as condensed descriptions in a way to disclose meaning.

According to Van Manen (1997) there are several ways of performing thematic analyses. Brown et al. (1989) for example suggest that we can ask questions to the text and gather sections of the text that answer those questions. For this study I applied the method of

thematic analysis, whereby the whole text is read and divided into meaning units. A meaning unit according to Lindseth and Norberg (2004) can “be part of a sentence, a sentence, several sentences, a paragraph, i.e. a piece of any length that conveys just one meaning” (p151).

After I divided the text into meaning units, these were read through and reflected on against the meaning of the naïve understanding. Following the reading and reflection, the meaning units were condensed, i.e. the essential meaning of each meaning unit was expressed in everyday words as concisely as possible. During the next step according to Lindseth and Norberg (2004) these condensed meaning units:

“Are read through and reflected on regarding similarities and differences. They are then sorted and all condensed meaning units that are similar are further condensed and sometimes even abstracted to form sub-themes, which are assembled to themes, which are sometimes assembled into main themes” (p152).

The meaning units were condensed and discussed with my supervisors, and main themes, themes and sub-themes were identified. During the structural analysis I tried to view the text as objective as possible. I decontextualised the meaning units from the text as a whole, i.e. I considered the text parts as independently as possible from their context in the text. This is possible if the meaning units are long enough to contain one essential meaning. I sometimes found that a meaning unit contained more than one essential meaning, which entailed a further division (Lindseth and Norberg 2004, p150).

The formation of the themes is followed by a reflection on them in relation to the naïve understanding acquired at the first phase of the analysis. What the researcher is aiming from this reflection is to verify whether the themes validate or invalidate the naïve understanding. When the structural analysis invalidates the naïve understanding, then the analysis process is repeated; that is the whole text is read again and a new naïve understanding is formulated and checked by a new structural analysis. According to Soderberg and Norberg (1993) this process needs to be repeated until the structural analysis validates the naïve understanding. Based on the philosophy of Ricoeur (1976) that the text is multidimensional and there are many though not infinite meanings,

allows the researcher to perform several structural analyses in order to unveil various meanings.

Thirdly, a comprehensive understanding is formulated, “a more sophisticated mode of understanding emanating from and supported by the first two phases” (Ricoeur 1976, p74). During this phase the interpretation of the whole follows and involves reflecting on the initial reading along with the interpretive reading to ensure a comprehensive understanding of the findings. In formulation of the comprehensive understanding, the meanings in the text have evolved in a critical dialectic between the reader’s pre-understanding and parts and the whole of the text, and this understanding is re-contextualised in light of relevant literature to deepen and widen the understanding of the text (Lindseth and Norberg 2004; Ricoeur 1976).

The process of interpreting the text as a whole and arriving at a comprehensive understanding is the “nonmethodic” pole of understanding (Ricoeur 1976). It is not possible to follow strict methodological rules. Imagination is important (Lindseth and Norberg 2004). Again I came close to the text and recontextualised it. I tried to perceive it in the light of the literature text chosen and also see the literature text in the light of the interview/focus group text. The focus is not on what the text says but on the possibilities of living in the world that the interview text opens up. The focus is more on the future than on the past. Data analysis was continuously informed by my personal experience, also from reading the literature and from engaging in discussions with similarly experienced colleagues. Therefore, the processes employed for data analysis occurred in a reciprocal way rather than as discrete activities.

Below, I provide an example of the actual analysis process that was employed as part of this study. The analysis includes parts of Ms Eleni responses to the meaning of quality nursing care. The patient’s responses are related to two main themes, which appear separately in the next chapter however, for the sake of this example these are presented together here to illuminate the analysis process.

Naïve reading

Reading the text, in a naïve way and with an open mind, the patient appeared to relate quality nursing care with the feeling of reliance on nurses and, the availability of beds and the accessibility to health services. The patient has stressed in her interview two main aspects of the care, one relating directly to the nurse and nursing care and a wider one concerning the administrative aspect of the health care services.

Table 5.1. Example of Structural Analysis (thematic analysis)

Meaning Units (condensed)	Sub-themes	Themes	Main Themes
<p>A. [Quality Nursing Care is] Feeling that I can rely on nurses on every single moment to take care of me, whatever I need and whatever my illness requires [...]</p> <p>B. However equally important is having beds available and access to the appropriate resources for us. The ministry needs to take into consideration the people rather than just the financial statements [...]"</p>	<p>A.1. Sense of security – trust towards the nurses and the staff in general. Trust for the nurses' skills and abilities.</p> <p>A.2. Proximity</p> <p>A.3. Ability to meet the patients needs.</p> <p>B.1. Availability of services.</p> <p>B.2. Policy and strategic planning from the Health Ministry to meet the needs of the patients with cancer.</p>	<p>A. Nurses need to have certain qualities to care for the patient.</p> <p>B. Availability and access of services.</p>	<p>Being cared for by clinically competent nurses.</p> <p>Receiving care in easily accessible cancer care services.</p>

Structural Analysis (thematic analysis)

The structural analysis verified the naïve understanding of the text. The narrative revealed that the patient has attributed more than one meaning to quality nursing care. She elaborated on certain qualities/competencies that nurses should have by commenting that “[...] *take care of me, whatever I need and whatever my illness requires [...]*” in order to be able to meet her needs and make her feel safe through their clinical practice and as a result “ [...] *I can rely on nurses*”. Another meaning she attributed to quality nursing care was the need to have available and easy accessible cancer care services. “[...] *having beds available and access to the appropriate resources for us*”.

Comprehensive Understanding (Interpreted whole)

The interpreted whole is related to appropriate literature. This literature includes the work done on the meaning that patients give to the term quality nursing care. Oermann (1999) performed an explanatory study with patients using an interview with four open-ended questions and scales for rating their health care in the last 6 months taken from the Patient Assessment of Health Plans (CAHPS) Adult Core Questionnaire. Patients interpreted quality nursing care as having nurses who were concerned about them and demonstrated caring behaviours, were competent and skilled, communicated effectively with them, and taught them about their care. Oermann (1999) found that availability and access of care have been used by the patients to describe quality of health care in general rather than to describe quality nursing care. In my study, I have found that the patients interpreted the term of quality nursing care in a similar way. As with Oermann’s study, patients viewed the notion of quality of nursing care as having skilful and caring nurses dealing with their treatment, providing them with information and necessary teaching, and communicating effectively with them. Contrary, to the Oermann study, patients in this study have also used the availability of resources and access to care as composing elements of quality nursing care. The themes of availability and access to resources used by the patient in order to describe the term of quality nursing care came as no surprise. The reason lies in the changes and reforms that have been introduced in the Cyprus HCS and particularly the cancer care services since 2003. The decisions driven by the

political and economical arena to decentralise cancer services and in some cases to interrupt the operation of some cancer centres (Karakatsani, 2004a) have negatively influenced, according to the patient that I interviewed, not only the quality of care but also the way patients view their health care providers. This has, in many cases led to conflict between patients and the MoH (Karakatsani, 2004b, 2004c).

Other studies have found that patients seemed to value competence, knowledge and technical skills in terms of quality. Irurita (1996) and Attree (2001) reported in their studies that patients identified different levels of quality that depended on contextual and intervening conditions linked to environment, organisation, and the personal characteristics of both staff and patients. A study performed by Radwin (2000) aimed at exploring patients with cancer perceptions of quality nursing care. Eight attributes of quality nursing care emerged from the data. From the patient's perspective, quality nursing care was characterised by professional knowledge, continuity, attentiveness, coordination, partnership, individualisation, rapport, and caring. In addition, two outcomes of quality care included increased fortitude and a sense of well-being with its constituents of trust, optimism, and authenticity.

Studying the ethnohistory of Cyprus, one realises why patients are so politically driven and argue in relation to accessibility and availability issues. This is not confined solely to the patients with cancer, but is rather a general phenomenon that has been shaped through the passing of time and the circumstances under which Cypriots had to live. During the 10000 years of their history, Cypriots have been suppressed by foreign invaders and conquerors. Cyprus has been independent only for a period of 14 years after its independence from the British rule in 1960, a fact that led them to become very sensitive in relation to their rights. What characterises Cypriots is their continuous fight for freedom and their right to exist as an independent self governed nation. This is why, at a micro level we fight for justice, legal and human rights. This mentality has been implanted in every Cypriot and here lies the reason why patients did not accept the changes that the MoH was trying to impose on them, as was previously discussed.

Therefore, they actively reacted by founding two cancer patients associations⁸³ in order to protect their rights and improve the quality of the care provided to them. The patients and their families were not willing to jeopardise the safety and the quality of care provided by the health services and therefore they have recently founded the E.L.A.ZO association in order to be able to take more active measures (Kasinidou 2006b).

Rigour

Silverman (1998) comments that in qualitative research, issues of validity and generalisability are essentially the same as those in quantitative studies; establishing the truth of accounts (in that they represent some reality outside the research itself) and adding to theory (in that the findings are applicable to a population or setting wider than that of the study). In contrast, Dempsey and Dempsey (2000) state that the terms validity, reliability and generalisability are generally avoided in qualitative research and qualitative researchers prefer to use the phrase “truth and accuracy”.

One critical question in qualitative inquiry concerns the knowledge claim that can be made. Are the findings limited to the informants included in the study, or can the findings be generalised or transferred or are they applicable to other contexts or other people? The results of this study can not be generalised if one employs a statistical definition of generalisability dependent on sample size and representativity. However, if generalisability is understood as being on a theoretical and conceptual level, the understanding gained from this study may be transferable to people in contexts beyond those that were studied. Hopefully, the findings can convey understandings and descriptions enabling readers to see their own situation in a new, and expanded, way.

Another critical question is on what grounds we can believe the findings of a qualitative study. Different methodological traditions have somewhat different arguments for the credibility of qualitative findings. When it comes to hermeneutic phenomenology, Ricoeur (1976, p78) states that it is always possible to argue either for or against an interpretation, and the credibility of an interpretation lies closer to the logic of

⁸³ Cyprus Anticancer Association-*Αντικαρκινικός Σύνδεσμος Κύπρου* and Cyprus Cancer and Friends Association- *Παγκύπριος Σύνδεσμος Καρκινοπαθών και Φίλων*.

probability than to the logic of empirical verification. Credibility is argumentative and is established in a discourse. The findings of a study achieve credibility when other researchers come to regard them as sufficiently trustworthy to rely on in their own work (Kvale 1996, p245). Bruner (1996, p91) asserts that credibility in narrative research can also be understood as verisimilitude (i.e. lifelikeness), meaning that the interpretations appear truthful in comparison to one's own lived experiences and in relation to shared meanings in society.

The integrity of this work stemmed from the process of coding and categorising the data, with links made explicit and concepts defined. The fundamental point to be grasped in evaluating hermeneutic accounts is that there is no such thing as an interpretation-free, objectively "true" account of "things in themselves"⁸⁴, and that there is no technical procedure for "validating" that an account corresponds to this timeless, objective "truth" (Benner 1994). Ricoeur's notions of textual plurality and multiplicity explicitly indicate that engaging in a quest for the one objective and universal "truth" will most likely end up in failure, as the text becomes open to different interpretations and gains multiple meanings.

This is a qualitative study and validating procedures in their technical sense were not of any importance with the exception where the stem questions and some transcribed interviews were translated and back-translated. Through certain methodological decisions taken as part of this study a level of truth and accuracy was achieved. Data were triangulated in two ways. Firstly the data of the study sought from different independent sources (patients, nurses and key advocates). Secondly, the findings of the study were read and supported against the data of other research studies done in the same area of concern. Furthermore, informant verification was implemented in order to "verify" that the analysis has given a probable interpretation of the data. Five informants (2 patients, 2 nurses, 1 advocate) were randomly chosen from the sample in order to "verify" the analysis. During the "verification" process these informants were asked to read the results and verify that the meaning and core of their opinions and perspectives

⁸⁴ The traditional positivist definition of the correspondence theory of truth

had been correctly attributed in the analysis. In addition to informant verification, researcher triangulation was also implemented (Robson 2001; Shih 1998). As part of this method, 6 transcribed interviews were translated in English and sent to the supervisors for back translation. This process was done to assure that the terms, wording and overall meaning of the data were adequately and appropriately attributed. The researcher triangulation was achieved through the participation of myself and my supervisors in the analysis process.

The research data were analysed by introducing a “parallel blind technique”. This method allowed researcher triangulation since three researchers participated in the analysis process. In this case the technique was used to assure the truth and accuracy of the research data and the process of analysis. After I transcribed the interviews, these were sent to my supervisors. Then all three analysed the interviews independently by using the same method of analysis, as this was described earlier in this chapter. We then set up a meeting to compare our versions and to resolve any differences. Once we did so, we jointly agreed to the translation process and the findings.

Another central issue that contributed to the truth and accuracy of this study is reflexivity. According to Nightingale and Cromby (1999) “Reflexivity requires an awareness of the researcher’s contribution to the construction of meanings throughout the research process, and an acknowledgment of the impossibility of remaining outside of one’s subject matter while conducting research” (p228)

Ethical Considerations

I shall serve the Human and Social Justice with respect to the Human Rights and Laws of the state

(Part of the Greek-Cypriot Nurses’ Oath)

Ethical guidelines are especially important when informants are vulnerable people, such as people with cancer (Koivisto et al. 2002). People who are dependent on care are vulnerable, and subjecting them to research raises ethical considerations. Some researchers claim that patients with cancer should not be exposed to research while

others including myself assert that it is disrespectful not to give these persons the chance to convey their experiences if they wish to do so (Rasmussen 1999).

The permission to carry out the study was issued by the MoH. This endorsement provided access to the research sites and also ensured that an ethics committee reviewed the study. Specific access was also negotiated with managers of the specific clinical areas where patients and staff were asked to participate. A research protocol was examined and approved by the HSESC of Middlesex University.

When people rely on rules to protect them from harm they are not interested in pieces of paper, but in the conduct of the people who are supposed to be governed by the rules (Koivisto et al. 2002; LoBiondo-Wood and Haber 1994). The Nightingale dictum that the first duty of the researcher is to ensure that the research shall do the informant no harm, a principle also associated with the Hippocratic Oath “above all else, do no harm”, guided the study’s ethical aspects (Erikson and Millar 2005).

All the necessary actions were taken to ensure the protection of the informants’ basic human rights. Throughout the course of this study, data collection was preceded by ethical reflection with help of the following ethical principles: right to self-determination, right to privacy and dignity, right to anonymity and confidentiality, right to fair treatment, right to protection from discomfort and harm. Since each of these principles relate to the social and cultural lives of informants in addition to their physical well-being, these were selected to frame the ethical procedures of this study.

Right to self-determination. This is based on the principal of respect for persons. People were treated as “autonomous agents who had the freedom to decide without external controls” (LoBiondo-Wood and Haber 1994, p324). An autonomous agent is one who is informed about a proposed study and is allowed to choose to participate or not or withdrawn from the study at any point without penalty or other effects on their care or career (Sheridan 2000). The consent form was clear about the nature of the agreement that the informant and myself entered into (Polit and Hungler 1999; Raeve 1996). All

informants were individually informed about the study's aim, purpose and implementation strategy. At the end of this briefing their consent was ensured in written form (Polit and Hungler 1999). In those cases of some informants refusing to sign the documentation, an oral consent was given instead.

Right to privacy and dignity. Based on the principle of respect, privacy is the freedom of a person to determine the time, extent and circumstances under which private information is shared or withheld from others (Catanzaro and Woods 1987). Interviewing the informants at their own time and privacy satisfied these demands. Actions were taken during the interviews so that the researcher and informant could enjoy privacy. Questions were carefully designed in order not to offend the informants. The principle of respect for human dignity came to mean being cautious not to invade private space or cause suffering, and providing full disclosure about the research so that all informants could make voluntary and informed decisions about whether or not to participate.

Right to anonymity and confidentiality. Based on the principle of respect, anonymity exists when the subjects' identity can not be linked with their individual responses (Sheridan 2000). Confidentiality means that individual identities of subjects are not linked to the information they provide and are not publicly divulged. The collected data were anonymous and identified with code numbers to guarantee anonymity. Furthermore, the lists of informants' names, code numbers and consent forms were kept separately locked from the collected data so that subjects could not be identified by their responses (Dempsey and Dempsey 2000). Furthermore, the informants were informed that the research material could only be accessed by the researcher and his supervisors. Informants were also informed that I would use pseudonyms for the purposes of the transcripts. At the end of the study all documents will be destroyed.

Right to fair treatment. Based on the ethical principle of justice, informants were treated fairly during the study. The principle of justice aided in reflecting on the righteousness in asking informants to participate, and in making sure that the research was not being

intrusive. No promises of personal benefit were given, avoiding deception. Each informant was treated fairly and in the same way, as other informants. Fair treatment included equitable selection of subjects during the study. This included “selection of subjects for reasons directly related to the research topic versus convenience, compromised position, or vulnerability” (LoBiondo-Wood and Haber 1994, p323). During the interviews and focus groups I was fair with the informants by keeping to the interview schedule.

Right to protection from discomfort and harm. Based on the ethical principle of beneficence, people must take an active role in promoting good and preventing harm in the world around them, as well as in research studies (Nevidjon and Sowers 2000). The research practices sought to preserve freedom from harm by ensuring that informants did not feel pressured to disclose events they would prefer to remain private. I felt that there was no real prospect that the research informants would be harmed by the interview or focus method that were used, although it was possible that some informants might be distressed by discussion of certain aspects of their lives. I decided that if such distress became apparent I would ask the informant if they wished to terminate the interview, offer support, and inform the nurses before leaving the ward. In two cases I terminated the interview based on the reactions of the patient who even if they did not complain I judged that it was in their best interest to continue the interview some other day.

Conclusion

This chapter has provided detailed description of the methodological decisions that were taken during the empirical phase of the study. Special focus was given to the data collection process and the interpretation method. It was discussed how the decision trail was informed by the literature on hermeneutics and especially the philosophy of Ricoeur. Hermeneutics also informed the development of the findings which is the next chapter of the thesis.

CHAPTER 6

Explication, Presentation and Discussion of the findings

Introduction

The heading “data analysis” is deliberately avoided here, because “analysis” has particular connotations for hermeneutic phenomenology and phenomenology more generally. Explicitly the term “analysis” usually means a “breaking into parts” and therefore often means a loss of the whole phenomenon whereas “explication” implies an investigation of the constituents of a phenomenon while keeping the context of the whole.

In this chapter the data collected through this study are presented. A consistent way to present the findings was chosen. The main themes, themes and sub-themes were supported by citations from the transcripts’ text and then the existing literature was used to highlight and validate these.

This chapter focuses on the study’s results and develops in the following way:

- i) The demographic data of the patients are presented in the form of tables.
- ii) The demographic data of the nurses are presented in a table.
- iii) The explicated data collected from the interviews and focus groups are presented.

Data retrieved from patients and advocates are presented together as from the study it was shown that they share the same or similar views for the topic under investigation. A nursing response was then obtained for their view which is presented so that a discourse between patients, advocates and nurses is developed.

Even though the primary aim of this study was to identify and focus on those attributes of quality nursing care that informants appeared to agree upon by drawing upon a shared understanding of the world in which this kind of care can materialise, a considerable attention was also given to the emerged contradictions and inconsistencies in relation to these attributes.

Patient-Informants Demographic Data

In the study I included 12 female and 13 male patients with cancer. These informants were interviewed individually. Fifteen of these informants were further interviewed in groups (2 groups). Informants were patients who were diagnosed with cancer including breast, lung, prostate, stomach, testicle, intestine, liver and bone cancer. Patients were aged from 21 to 68 years. The duration of illness of all patients was 6 months to 3 years.

Their full demographic details appear below in tables 6.1 and 6.2.

Table 6.1. Patients' Demographic details

Patient Identification Number	Gender	Age	Occupation	Education Level	Cancer Site	Time of diagnosis (months)	Previous treatments in this department	Previous treatments in other department	Focus group participation
1	F	57	School teacher	University	Bones	36	YES	YES	NO
2	M	66	Farmer	Primary	Testicle	8	NO	NO	FG2 ⁸⁵
3	M	21	Student	University	Lung	6	NO	NO	FG1 ⁸⁶
4	M	68	Fruit supplier	Primary	Prostate	11	NO	YES	FG1
5	F	65	House-wife	No formal education	Breast	8	NO	NO	NO
6	F	21	Student	College	Intestine	36	YES	YES	FG2
7	M	62	Waiter	High school	Stomach	18	NO	NO	NO
8	M	21	Student	College	Testicle	12	NO	YES	FG1
9	M	58	Builder	No formal education	Prostate	11	NO	NO	NO
10	M	42	Chemical engineer	University	Intestine	12	NO	NO	FG2
11	F	58	House-wife	College	Liver	8	NO	NO	FG1
12	F	30	IT	University	Breast	6	NO	NO	NO
13	F	44	School teacher	University	Lung	24	YES	YES	FG2
14	M	57	Park ranger	College	Liver	18	NO	YES	FG1
15	M	68	Gardener	High school	Prostate	8	NO	NO	NO
16	F	42	IT	University	Intestine	24	YES	YES	FG1
17	F	62	House-wife	High school	Breast	12	NO	NO	FG2
18	M	44	CYTA employee	College	Intestine	11	NO	YES	NO
19	M	30	Builder	No formal education	Stomach	18	YES	YES	FG2
20	F	58	House-wife	Primary	Breast	6	NO	NO	FG1
21	F	68	Civil servant	University	Lung	12	NO	YES	FG1
22	M	65	Civil servant	University	Stomach	11	NO	NO	NO
23	F	58	Waiter	High school	Lung	18	NO	YES	NO
24	M	66	Civil servant	College	Prostate	6	NO	NO	NO
25	F	68	Farmer	Primary	Breast	18	NO	YES	FG2

⁸⁵ FG2 – Focus Group 2, Nicosia (7 informants-3 male, 4 female)

⁸⁶ FG1 – Focus Group 1, Limassol (8 informants-4 male, 4 female)

Table 6.2. Days that patient spend in the hospital from admission up to the day of the interview

DAYS OF TREATMENT (days required to stay in the hospital)	NUMBER OF PATIENTS
2	6
3	8
4	2
5	2
7	3
10	2
14	2

Nurse-Informants Demographic Data

Ten male and 10 female nurses participated in this study. Due to the fact that two out of the three cancer centres were situated in Nicosia, the majority of the nurses (16 = 80% of the sample) worked in Nicosia and the remaining 4 (20%) worked in Limassol. Nurses were individually interviewed as mentioned in the previous chapter. Their demographic details appear below in table 6.3.

Informants were registered nurses working in cancer care departments with 16 nurses having diploma education and 4 having degree education. Nine staff nurses and 11 nurse managers comprised the study sample. They ranged in age from 22 to 54 years and had worked from 1 to 15 years in cancer care.

Table 6.3. Nurses' Demographic details

Nurse	Gender	Age	Marital status	Placement of work	Rank	Nursing Qualifications	Previous experience in cancer care	Educational background (nursing)
Nurse 1	Female	22	Single	L.G.H	Staff Nurse	GN ⁸⁷	1	SNG ⁸⁸
Nurse 2	Female	25	Single	N.G.H	Staff Nurse	GN	5	UE ⁸⁹
Nurse 3	Male	27	Divorced	N.G.H	Staff Nurse	GN-OT ⁹⁰	7	SNG
Nurse 4	Male	30	Single	B.O.C ⁹¹	Staff Nurse	GN	1	SNG
Nurse 5	Female	28	Married	N.G.H	Staff Nurse	GN-OT	7	SNG
Nurse 6	Male	31	Divorced	N.G.H	Staff Nurse	GN	1	UE
Nurse 7	Female	31	Married	L.G.H	Staff Nurse	GN	1	SNG
Nurse 8	Female	40	Married	N.G.H	Ward Manager	GN	8	SNG
Nurse 9	Female	35	Divorced	N.G.H	Staff Nurse	GN	2	SNG
Nurse 10	Male	37	Married	L.G.H	Staff Nurse	GN	4	UE
Nurse 11	Male	39	Married	B.O.C	Ward Manager	GN	1	SNG
Nurse 12	Male	35	Divorced	L.G.H	Ward Manager	GN	6	UE
Nurse 13	Male	50	Married	B.O.C	Ward Manager	GN	7	SNG
Nurse 14	Female	45	Married	N.G.H	Ward Manager	GN	14	SNG
Nurse 15	Male	41	Married	N.G.H	Ward Manager	GN	11	SNG
Nurse 16	Female	50	Married	B.O.C	Ward Manager	GN	4	SNG
Nurse 17	Male	55	Married	B.O.C	Ward Manager	GN	10	SNG
Nurse 18	Female	51	Widowed	B.O.C	Ward Manager	GN	5	SNG
Nurse 19	Male	54	Married	N.G.H	Ward Manager	GN	12	SNG
Nurse 20	Female	54	Married	N.G.H	Ward Manager	GN-OS ⁹²	15	SNG

⁸⁷ GN-General Nurse

⁸⁸ SNG – School of nursing graduates

⁸⁹ UE – University Education

⁹⁰ GN-OT – General nursing with oncology training (less than 6 months)

⁹¹ B.O.C Oncology-Bank of Cyprus Oncology Centre

⁹² GN- OS - General nursing with oncology specialisation (more than 6 months)

Explication of the Data

The explication of the data from the individual and group interviews was performed with a hermeneutic phenomenological method informed by Ricoeur's Interpretation Theory and with the Greek-Cypriot cultural perspective (identity) of the informants (and the researcher) also informing the explication process. The aim of this method is to interpret, in other words explain the meanings of a phenomenon as it appears in the text. The principles of the Hermeneutic Circle⁹³ informed the interpretation process. Hence, the interpretation of the text consisted of the dialectical movement between understanding the whole text and explaining the parts of the text. The interpretation included three phases: naïve reading, structural analyses (explication) and comprehensive understanding.

The explication process through which each main theme was developed is presented in detail. The process is not as linear as it is presented in this description. A wide body of literature supports the use of this approach for presenting research data, as it is easier for the reader to understand (and visually follow) the explication process instead of losing the track in complicated philosophical processes involving imagination and intuition (Ericson-Lidman et al. 2007; Brannstrom et al. 2007; Lindblad et al. 2007; Hellzen et al. 2004; Lindseth and Norberg 2004; Strandberg and Jansson, 2003). The findings presented are those considered as the most "probable" and I do not mean in a statistical sense, but in the sense that Ricoeur has suggested; that is the interpretations that are most probable to be true. The decision as to which interpretations are the most (or more) probable derived through the informants' perspectives discourse, round table discussions with my supervisors, and the feedback received through several conference presentations of the findings.

⁹³ Also see chapter 2 on Hermeneutics

Overview description of findings

The data explication revealed that the patients, their advocates and the nurses in cancer care departments interpreted the meaning of quality nursing care in terms of the following main themes:

- Receiving care in easily accessible cancer care services.
- Being cared for by nurses who effectively communicate with them and their families and provide emotional support.
- Being empowered by nurses through information giving.
- Being cared for by clinically competent nurses.
- Nurses addressing their religious and spiritual needs.
- Being cared for in a nursing environment which promotes shared decision-making.
- Patients being with and involving the family in the care.

The results are formulated and presented in everyday language as close to the lived experiences expressed in the narratives as possible. Everyday language originates from essential lived experience. In hermeneutic phenomenology, according to Lindseth and Norberg (2004, p151) “when we try to express the meaning of lived experience we therefore use everyday language rather than abstract well-defined scientific language. Verbs are better at revealing lived experience than nouns”.

Receiving care in easily accessible cancer care services⁹⁴

Naïve Reading

The text⁹⁵ was read several times in order to grasp its meaning as a whole. A naïve understanding was formulated of the meaning of quality nursing care as follows:

⁹⁴ In Greek – *Lipsi frontidas se efkola prosvasimes ypiresies karkinou* – Λήψη φροντίδας σε εύκολα προσβάσιμες υπηρεσίες καρκίνου.

⁹⁵ Transcribed material.

The patients and their advocates raised issues such as government policies and strategies, resources, and hospital policies and believe that these influence their understanding of the concept “quality nursing care”. These issues raise problems that not only retrospectively negatively influence their health but also influence their satisfaction levels.

Patients discussed quite openly the Cyprus HCS and were not surprised by issues of scarcity. As with other systems in the world Cyprus rations health care, by waiting times, by availability of services, coverage decisions, or by ability to pay. These are therefore some of the reasons for some resources being unavailable, as choices will have to be made whenever demands exceed resources. It seems that patients are struggling when it comes to accessing the cancer care services (where available) especially those living in rural areas. It is not unusual that sometimes due to the lack of transportation means, treatment sessions were missed or cancelled which has influenced their treatment effectiveness and outcomes. Patients commented that they were not the only one to suffer from these problems since these extended to include their families as well. They spoke about financial problems, relationship problems, work and social problems that arose for the patient’s family.

As soon as the naïve understanding of the text (whole) was formulated the explication moved to the next phase, the structural explication; in terms of the hermeneutic circle the parts that consisted of the naïve understanding were searched and identified in the text. The phase of structural explication served to validate or refute the initial understanding obtained in the naïve reading and explain what the text is saying. Therefore the transcribed text was divided into meaning units, that is, one sentence, parts of sentences or several sentences with a related meaning content. The movement from the parts (themes and sub-themes) to the whole (main theme) is presented in table 9-Appendix C.

I abstracted the meaning units in some way to make them concise, that is, the meaning units may be a long passage or paragraph and then I precised it down to some words to

make them more understandable, I asked myself what the text said. After I have “collected” meaning units with the same content and condensed them, I interpreted what the meaning units were telling me in a further interpretative way and then grouped these utterances together into groups, that is, sub-themes. After this I interpreted what the sub-themes were telling me and then grouped them together in themes on a further interpretative level. Finally the themes were similarly grouped together to form the main theme, a process shown below:

Meaning Units → Sub themes → Themes → Main Theme

Field notes: The patients and their advocates sometimes commented in an irritable way their opinions’ on this matter. Their anger derived from the fact that the government appeared to pay no attention to their real needs and problems. A possible reason for raising this matter with me was perhaps because the informants viewed this study as a means to make their problem public and voice their concerns through an empirical research. In relation to the way this links to the role of the nurse there are two possible interpretations. Firstly, it seems that patients see the nurses as part of the system and therefore being able to influence decisions on what services are available and how these are accessible. Alternatively, the reason of referring to this issue is that the nurses’ ability to provide quality nursing care is influenced by forces outside their control.

Structural Explication⁹⁶

The patients and their advocates expressed the view that the availability of appropriate cancer services which can easily be accessed is closely interlinked to quality nursing care. However, they feel that their care is in most cases deprived of such provisions by the government, the MoH and the hospital often leading to the development of problems for them and their families. The following themes were formulated:

A. Geographical inequalities for availability and access to cancer care services

The informants believe that there are inequalities when it comes to being able to receive treatment and accessing cancer care services in Cyprus. Patients from rural areas seem to

⁹⁶ See appendix C-Table 9

experience the biggest problems when they need to get treatment for cancer. Problems are also experienced by patients from urban areas and especially those cities (Paphos, Limassol and Larnaca) that are located in great distance from the capital Nicosia, where the majority of the specialised cancer services have been centralised. Therefore, the patients have to travel great distances and pay significant amount of money to get cared for. Many times treatments are postponed due to the inability of the patient to be present at the hospital or due to the inability of the services to meet the demand.

B. Family burden from taking the patient for his/her treatment and assuming responsibility for other aspects of the care

Apart from the financial cost, it seems that the family which often assumes responsibility for the patient experiences other forms of burden. The patient expects his/her family to support him/her in any possible way during the course of the illness, this be financial, physical or emotional support. The patient and his/her family seem to suffer from psychological distress. The sources of this psychological pressure derived mainly, due to the reliance on the relatives for support and their commitment to provide support due to the collectivist Greek-Cypriot society and family. The chronic nature of the illness is translated for the relatives as having financial, time, emotional and social costs. Relatives need to spend time away from their own families in order to be able to take the patient to the hospital and be with him/her. In some cases the relatives' partners however, can not endure this situation and as a result problems may arise in the family. These can take the nature of arguments among the couples or negative reactions from the children towards the father or the mother (patient's relative) because of the limited time they spent with them. When the patient expects his/her children to take him/her to the hospital for treatments or check-ups, financial problems may also arise. These are created because the relative takes frequent unpaid leaves from his/her work while at the same time he/she may also has to pay for the patient's transportation expenses, medications or even to provide full financial support for the patient due to his/her inability to work.

C. Family's presence, which is recognised by the patient as an important factor during hospitalisation, is negatively influenced by poor access

The informants acknowledged in the discussions the invaluable role of the family during the course of the illness. For the informants, family is a supportive mechanism for both physical and emotional support while for the nurses the family can be a “facilitator” for their job. “[...] of the facilitating role of the family” (FG with PA). What I mean by “facilitator” in this case is that when the relatives are present and involved the patient seemed to be more accepting of the care provided. Family has the ability to “[...] make them feel safer and relaxed [...]” (F-44, P1-13). The informants argued however, that accessibility and availability problems to the care weaken this important role of the family. Strict visiting hours imposed in the cancer care departments and the need to travel great distances to see their ill relatives reduce the possibility of the relatives to being with the patient.

D. Political decisions lack planning and create inequalities.

The nature of the Cyprus HCS allows the decisions to be taken exclusively by the MoH, whose minister is a political person⁹⁷. This often creates conflicts and dilemmas between what is beneficial for the people and what is beneficial for the political party's profile. “They opened the cancer department in Limassol but the range of care provided is limited [...] it is something that was done just for the people's eyes” (F-57, P1-1). An example of this was the rationale for the introduction of a specialised cancer care centre in the capital instead of other locations more suitable for the majority of the population. Another problem that arises from the decisions being taken at a centralised level (MoH) is that, often the needs of the patients and their access problems are not appropriately evaluated, which leads to poor planning that fails to address these problems. For example, the centralisation of radiotherapy services forces the patients from rural and

⁹⁷ Political person: In Cyprus this is translated as a person belonging to one of the political parties that participate in the government.

urban areas to travel to the capital city to be treated, whilst a local centre would lessen the problem of travelling for many patients with cancer.

E. *“Quality nursing care” is interpreted as being able to access the cancer services which are widely available.*

It seems that regardless of the concept being predominately a nursing concept, the informants hold a more general idea of the concept of quality which includes administrative issues such as access and availability of resources and services. “[...] we have to wait for hours and sometimes even days just to get a bed in order to be treated? That most of us have to travel away from our cities to get treated?” (M-21, P1-3, FG-1). They value these issues greatly and therefore argue that there can not be “quality nursing care” without having available and accessible cancer care services.

Comprehensive Understanding

The comprehensive interpretation is based on my pre-understanding, the naïve understanding, the main themes, themes and sub-themes and reflected on in relation to the context of the study, the research question and literature and is expressed as follows:

One understanding of the meaning of quality nursing care, as disclosed through patients’ and advocates’ narratives, is that quality nursing care is closely related to issues such as availability and (fair) access to cancer services. Although “fair access” can be characterised simply as providing the right service at the right time and in the right place (Rogers et al. 1999, p866) it is a complex concept covering the provision of services, the knowledge and opportunity to use them, and the measurement of need (Gulliford et al. 2002, p186). Based on the issues raised in the narratives I concluded that the informants were referring to the latter meaning of access to services. Oermann (1999) in a qualitative study interviewed 239 patients on their perspectives of quality health care and quality nursing care. Patients defined the quality of health care in terms of access to

care confirming the fact that quality nursing care can also be viewed by the patients (and the advocates) as been related to issues of availability and access to services.

Based on my pre-understandings I did not expect the informants to raise such issues when asked for their interpretation of the “quality nursing care” concept which in my view would refer mainly to those aspects of the care that are influenced by the nursing profession. The fact that I am a nurse has influenced this pre-understanding of what the concept of “quality nursing care” should include and what not to include. Thinking ahead as a nurse, I had in my mind what a nurse does in order to achieve quality instead of what the patient is experiencing or desires. However, when such (administrative/political) issues were raised I was convinced based on the ethnohistoric element of “freedom” that the informants would criticise the government, its plans and policies. Based on this element, the Greek-Cypriots have become less tolerant when their basic rights are for any reason been threatened. Through the passing of time they have become more educated, knowledgeable and demanding in terms of the money that is spent for their health care, the actual care and its quality that they receive. They believe that receiving quality nursing care regardless of any limitations (e.g. geographical inequalities) is their basic right and they are not willing to compromise with anything less.

Accessing cancer care services in Cyprus is according to informants, problematic for specific groups such as people living in remote areas with low incomes, pensioners, elderly, people with physical disability and lone people. Poor patient access to cancer services worsens when these factors are combined. For example it was found that lone elderly patients appeared to face many problems in accessing cancer services. Elderly patients (men and women) with no access to a car considered, travelling to get treated as a burdensome experience but also a financial burden as well. Conversely, for younger patients travelling was not reported as a problem because these patients appeared to have a better access to a car. Informants assert that the problems of availability and access create inconvenience not only for the patients but for their families as well. Advocates comment that at the moment there is an inability of the MoH to provide home-based

care⁹⁸ to these people. Such care is solely provided by volunteered organisations and these do not have the necessary support by the government to care for all the patients⁹⁹. Research carried out in the U.K on rural patients travelling to cancer centres has highlighted that distance is not only perceived as an inconvenience (Hinds and Moyer 1997) but in some cases, patients have reported that they “face a trade-off between receiving specialist treatment or care in their local area” (Bain et al. 2002, p372). The Bain et al. study suggests that patients with limited or no access to a car are experiencing additional problems in accessing the health services. On the same issue, a study by Jordan et al. (2004) asserts that in any area (urban or rural), the greatest disadvantage is likely to be experienced by individuals without access to a car (including members of one-car households without daytime access). According to Greene and Monahan (1982, p423) and Hook et al. (1982, p426) the distance-travelled time is an important factor of visitation. With the declining availability of public transport it is likely that a private car is the only convenient way to travel in rural and urban Cyprus, indicating the increased problems that patient and family experience when they have limited or no access to a private car.

Hurst et al. (2007) in a study investigating the resource availability and equity in Italy, Norway, Switzerland and the U.K concluded that resource unavailability was a common phenomenon for all health care systems under investigation. Resource availability was unevenly distributed: some interventions were more frequently unavailable, and some patients were identified as more likely than others to be denied care on the basis of cost. Similarly cancer services in Cyprus are experiencing the effects of the unevenly distributed resources (Kyriakidou 2005; Alexandrinou 2005a, 2005b, Mitsopoulou 2005). Scarcity of medication, beds in the specialised centres, specialised nurses and physicians are only some of the problems experienced by the cancer services, which in turn affect the access of patients to these services and their right to be treated whenever and wherever necessary. As with the findings of Hurst et al. (2007) that suggest that in the face of scarcity, and despite scarcity-related adverse events, physicians accepted

⁹⁸ Community based cancer care

⁹⁹ Eligible patients are not selected based on their needs but rather on the coverage areas of residency where the private organisations operate.

cost-containment policies, and were willing to participate in cost-containment decisions, the MoH in Cyprus adopted a similar cost-containment policy (Panayiotou 2006).

The patients have commented on the MoH strategy which has in many cases, led to rushed and unplanned decisions for developing new cancer services which failed to come to a full operation and therefore failed to improve the situation for patients (MoH 2006; Charalambous 2006). Similar findings are supported by Beccaro et al. (2007) who assert that in the absence of a specific plan targeted at reducing inequalities, the simple allocation of funds for the development of new cancer and palliative services might even worsen the situation. My study has highlighted that the age of the patients seems to negatively influence the access to cancer care services. Older patients seem to suffer the most as they are more likely to be dependent on others (i.e. family and significant others). In the literature there are studies that support this finding. Grande et al. (2006) for example in a quantitative study explored the influence of patient age in access to palliative care services. They concluded that “whilst cancer is a major determinant of access to palliative care, both older patient care and older carer age were associated with worse access to palliative care” (Grande et al., 2006, p271). This result confirms previous findings that patient age is negatively associated with cancer palliative care access (Owen 2005; Grande et al. 2002; Addington-Hall and Altmann 2000).

A study by Beccaro et al. (2007) investigated the inequalities in the provision of and access to palliative care for patients with cancer in Italy. The study highlighted the fact that access and referral to specialist cancer and palliative care services are unequally distributed among patients (p78). The same study also concluded that patients are less likely to receive specialised care if they are elderly, of a low socio-economic status, poor functioning and a high nursing care requirement. These findings validate the findings of this study and the findings of previous studies (Ahmed et al. 2004; Grande et al. 1998). Moreover, Beccaro et al. (2007) assert that geographic variations in the availability and provision of specialised cancer services is also present in other countries where there has been a rapid and unplanned development of services and programs.

The informants in this study emphasised some of the problems they face due to their need to travel to get specialised treatment. According to Hubbard et al. (2006) there is a scarcity of research on patients' experiences of transport and travelling for treatment but the little that has been conducted indicated that some patients experience difficulties. For example, a recent study by Allirajah et al. (2005) in the U.K highlighted that patients with cancer often have to travel in order to get treatment. As a result the patients and their families are burdened with the financial costs that this travelling entails. In the same light, Guidry et al. (1997) showed that availability and affordability of transport was perceived as a barrier to the uptake of treatments. These findings coincide with the alarming finding from my study according to which few patients reported that there is an impact on their family due to the distance from cancer services. According to a male patient age 66:

"[...] My daughter said nothing to me but I am sure the problems arose because she has to drive me here once a week for the chemotherapy and radiotherapy. Her husband does not so understand of the whole situation and for this they keep fighting...I do not know what to do so this makes me anxious and reluctant to come to get the treatment sometimes, last week I pretended that I was not feeling very well just to skip the treatment and save my daughter from driving me here" (PI-2, FG-2)

On the same topic a female patient, aged 21, commented the following:

"I do not have to think just myself. I have also two young children to think of. Travelling to get treatment is not easy, I know that it is necessary, but my life has become more complicated since I got cancer. My children, and myself, feel that they do not have a mother anymore, due to the treatment and the travelling I have to be away from home quite some time. Each time I need someone to stay with them because my husband is working and believe me it is not easy nor is something that I like, the Ministry must see these problems and act upon them, I do not know how but they have to do something" (PI-6)

Hubbard et al. (2006, p391) assert that for a minority of patients coming from rural areas, “distance from cancer services has led to family disruption by having to spend time away from families during treatment visits” confirming the findings from this study. Consecutively family disruption can cause psychological distress in relation to the person’s family responsibilities (Lock et al. 2005 as cited by Hubbard et al. 2006).

The patients’ text discloses, that for patients, these issues promote their dependency on others (i.e. family members and significant others) which in turn creates a loss of self-determination and it is a hardship to rely on others. Dependency on others is a burdensome responsibility for families and significant others. Strandberg and Jansson, (2003) assert that for relatives, dependency on them is revealed as evoking feelings of guilt and insufficiency and of being constantly concerned and worried. It is a struggle to be patient and understanding, having the difficult task of putting oneself into the dependent patients’ shoes in order to cope with the demanding task of balancing between helping the patient and not upsetting their own family’s lives. It is a burden to have someone’s depending on you. The interpretation, however, showed that patients revealed an important aspect of their care, which was not openly highlighted, that of the family assuming the care of the patients as informal caregivers. “[...] *I rely on them [family] to take me to the hospital; among the many things they do for me*” (F-44, PI-13). Therefore, the issues been raised above such as transportation, financial support of the patient, being present at the hospital consisted only a part of the burden experienced by the family. Their main source of burden seems to derive from their role as informal caregiver, especially in the “direct care¹⁰⁰”, that they assume or have to assume because the values of the Greek-Cypriot society expected them in doing so. Reflecting on the ethnohistoric review of the Greek-Cypriots, it becomes explicit that they tend to live their lives in accordance with their values.

¹⁰⁰ Given et al. (2001) assert that “direct care” is carried out directly with the patient such as symptom management, emotional support, administration of medications, and assistance with mobility or bathing.

When they face a decision and choose A instead of B, it's often because A feels right to them. They might use words such as, "it's the right thing to do", or "that's the right way". Family is according to this review one of the most important values for a person living in Cyprus and he/she tries to live his/her life in accordance to this value, avoiding those actions that may betray in any way the value of family. With evidence showing that the role of family in Cyprus is changing, there are now more women at work, there is a changing in the roles that the women adopt which may also have an impact on the patient, the woman and the family as a whole. Despite their changing roles women have not given up or disclaimed their role as carer for the family. It is evident in this study that this changing of roles has a negative impact primarily on the family and less on the patient. Women often as it was confessed in the narratives struggle to be with their patient even if sometimes to the expense of their own family and their jobs. Kanavou (2006) asserts that a value is an enduring belief that a specific mode of conduct is preferable to an opposite or converse mode of conduct or end-state of existence, and a value system is an enduring organisation of beliefs concerning preferable modes of conduct or end-states of existence along a continuum of relative importance. According to Maiese (2003) a value identifies those objects, conditions or characteristics that members of the society consider important. Therefore, caring for a family member reflects the values of respect and support of friends and family.

A Greek study assessed family evaluations, perceptions and attitudes on management, care and disclosure for terminal stage patients with cancer (Mystakidou et al. 2004). The study confirmed that cancer is not a disease of an individual but impacts the family system. Families must confront, and attempt to realise the meaning of cancer for the patient, for each family member individually and for the family system as a whole. Hence, the Greek family experiences burden from assuming the care of its ill member. In those cases where the patient is incompetent, conflicts of interest may arise since decision-making is a great responsibility for the family. According to Mystakidou et al. (2004, p5) "a relative, who feels guilty or denies the hopelessness of the situation, may press the patient for cure rather than care, or to prolong or discontinue treatment". Bean et al. (1980) in a study exploring the coping and supporting mechanism that patients

with cancer apply concluded that family and friends are considered to be among the strongest supportive mechanisms engaged by the patients when cancer occurs, and this may create burden for the family whilst the patient experiences distress when he/she is deprived of his/her family. Belou-milona et al. (2001) concluded in a quantitative study in Greece that the deprivation of the family members' presence could be a major factor affecting the hospitalised patients social interaction and personal well-being. Thus, it is very important to maintain family, social and personal relationships to the highest degree possible after hospitalisation. A factor that may affect the relatives' visitation is according to the researchers the psychological support of their patients. Belou-milona et al. (2001, p3) assert that "several times the patients may want to speak directly to a family member to share their feelings and concerns about their condition and their health problem and to receive encouragement". The lack of visitation from any patient or the restricted hours creates problems. Kelley et al. (2000, p21) assert that in addition to "family visitation on a special care unit indicates a sense of duty to "be faithful" and to foster a sense of family through ongoing relationships and family ties". Visitation policy is an issue that informants also raised in my study as a barrier to the ability of the family to be with their patient, however this will be further discussed in main theme 7.

The findings of my study resonate with these studies that have indicated that access and availability difficulties may lead to burden experienced by the family from the responsibilities they assume (or the changes in their roles) and for the patient due to the limited support he/she receives from the family.

According to the comprehensive understanding, nurses through their practice need to address those factors that fall under their control or advocate for those they can not control in relation to the availability and access to cancer services. Nurses' actions need to aim at maintaining and promoting the support the patient receives from the family, friends and significant others. Possible ways for dealing with the problem is adopting a flexible visitation policy, advocating for a transportation service for those who can not afford or do not have access to a car or advocating for a home care service.

Even though these issues were highlighted by the majority of the informants as being relevant to the interpretation of quality nursing care, the importance of these on what constitutes quality nursing care seemed to vary among the informants. Therefore, it was shown by the results that patients that lived in Nicosia or nearby cities (with good transportation connection with the facilities) even if they acknowledged the importance of availability and access issues to quality nursing care they did not emphasise on these issues. This indicated the fact that these patients and their families could access the cancer care facilities easily and without any particular problems, however in the narratives they seemed to be troubled by other attributes of quality nursing care such as being cared in an environment which could promote shared-decision making and receiving adequate information. Others however, were concerned about been able to have their family nearby when being cared for and where possible to provide the opportunity to the family to be actively involved in their care.

Patients that were treated in the participating departments for the first time also appeared not to be concerned by access and availability issues. This fact may have influenced their perceptions on what good access and availability are, since they had no prior experience of accessing these departments which perhaps contributed to the formulation of low expectations. On the contrary two patients that had been treated in cancer care departments abroad and apparently had high expectations on the availability and accessibility issues, criticised in their narratives the conditions under which they accessed the services.

Nurses' response to the patients' need for easily accessible cancer care services

Naïve Reading

Nurses responded to the views expressed by the patients and their advocates in relation to poor availability and difficulties to access cancer care services. A naïve understanding was formulated of the nurses' response as follows:

The nurses in their majority disagreed with the view expressed by the patients and their advocates in relation to the meaning of quality nursing care which is perceived as

availability and access to care. In the narratives the nurses defended the independence of the nursing profession against issues of availability and access to care. They strongly supported the view that the nursing care begins once the patient has accessed the services and not before that. As a result quality needs to be defined and assessed once the patient begins to receive care from the nurse.

Talking in broader terms the “quality of care” may include issues of availability and access however, it is according to the informants a different and more general concept which includes the totality of the health care team rather than “quality nursing care” which is an explicit concept referring to nursing in absolute terms.

Structural Explication¹⁰¹

Through the narratives the nurses believe that availability and access to services are not and should not be constituents of “quality nursing care”. It seems that the nurses have strong feelings about this particular issue, and this is confirmed by the absence of opposing views by any of the nurse-informants.

A. Quality is achieved through nurses caring

Among nurse informants there was a general feeling of disagreement with the patients’ and advocates’ expressed views that availability and access is part of the nursing care quality they receive. Nurses believe that nursing care is a separate dimension of the health care and should not be confused with other components such as issues of availability and access. “*I can hardly see the connection between quality nursing care and access*” (M-31, SNI-6). These aspects are managed by others and mainly if not exclusively by the MoH which is responsible to allocate the necessary resources. How and where these resources are allocated is a matter of political decisions which do not always respond to the needs of the patients.

Another issue that nurse-informants stressed was their belief that nursing quality begins to take shape as soon as the nurse assumes the care of the patient on his/her arrival on

¹⁰¹ See appendix C-Table 10

the ward. In their view what happens before the patient reaches the ward is not a matter that should concern the nursing profession nor are the nurses able to influence what is going on during this “pre-hospital” phase.

B. Beyond the scope of nursing

As was discussed above, the nursing profession is not responsible for issues involved in availability and access, and the nurses do not have the power to control such issues. However, in the narratives a paradox was identified. Even though the nurses assert that they should not be involved in issues concerning such issues they emphasised their ability that they hold “*through constant contact with the patient*”. Through this the nurse may identify accessibility and availability problems that the patient may be facing. Since the nurse has no direct control over these issues, he/she can pass these to management for action.

One informant claimed that access and availability are constituents of a broader term used in health care, that of “quality care” but not for “quality nursing care”. The same informant argued that the patients often find it difficult to differentiate the two concepts, which often used interchangeably in casual discussions. This according to her appears to be the reason why the patients have related quality of nursing care with issues of access and availability of cancer services.

Comprehensive understanding

In this study nurses in their majority emphasised that quality nursing care is limited to the nursing behaviours and procedures and issues such as availability and access extend beyond the scope of the nursing profession. A possible interpretation of the way that nurses responded to this particular aspect of the care comes from the nature of the nursing context in Cyprus, as this was evolved from the beginning of the 20th century to our times. Two aspects of the Greek-Cypriot nursing context may have contributed to the perceptions expressed by the nurses in the narratives. Firstly, the long-lasting

struggle of the nurses to free themselves from enduring beliefs and unspoken rules that dominated the nursing profession and secondly, their struggle to strengthen the perception of nursing as unique clinical expertise with distinct areas of practice. The perceptions expressed by the patients and their advocates might have been interpreted as a threat to the efforts of nursing to achieve the above goals, and therefore triggered a negative response to the inclusion of issues of availability and access to the interpretation of quality nursing care.

There appears to be an oxymoron here. While nurses' advocate for a "holistic" care, they have this isolated notion of nursing which fails to take into consideration issues such as access to care. However, the literature suggests that access and availability are more general issues which are related to the quality of the care as suggested by Oermann (1999) and which can also negatively or positively influence the quality of the nursing care. She concluded that it is difficult to view quality in isolation, something that the nurses in this study have implied. Moreover, Kunaviktikul et al. (2001) in a descriptive study in Thailand developed a definition of quality of nursing care and determined how it is measured. Ninety six nurses from a university and central hospital participated. According to their findings, access and availability issues were raised by the nurses as an indicator of quality nursing care. This indicator was categorised into the group called "structure" based on the Donabedian model of quality. These studies therefore support that quality nursing care is linked to the quality of the whole health and illness experience of people.

A small percentage of the nurses however, acknowledged their role in access and availability issues. These nurses were young in age and a reason that contributed to their different opinions was their nurse training. *"I do not see the reason why not have a say when it comes to the access of our patients to the services...our position allows us to evaluate when problems occur and act upon them [...]"* (F-25, SN-2). Another nurse referring to the same issue asserted that *"I have been working in this department only for a year, but I must say I was shocked that my colleagues do nothing to participate in such issues. My nurse education has taught me possible ways to contribute to these aspects of the care and when I get the chance I do so"* (F-21, SF-1). Another factor that might

have influenced these variations among the nurses was the recent decision of the Ministry's of Health Nursing Division to include several informational lectures for the nursing students. These younger nurses had the opportunity to participate in these lectures where the Head Nursing Officer welcomed their involvement in issues pertaining access and availability. This being a relatively recent trend in the nursing context in Cyprus, the nurses who gained their training prior of the initiation of this programme did not have the chance to be adequately informed and this perhaps negatively contributed to their perception of having a wider conceptualisation of quality nursing care.

Even if these issues appeared to be contentious for the nurses participating in this study, the literature review revealed that these issues have not been extensively researched from a nursing perspective. However, there are implicit associations that nurses are involved in issues such as efforts to improve the access of patients to health care services, and researchers believe that the nursing profession has an important role to play. These findings from the literature reinforced the valid arguments made by the minority of the nurses in my study.

Chapman et al. (2004) in a systematic review of recent innovations in service provision to improve access to primary care found that nurses had the ability to influence access. Explicitly, the nurses have contributed to improved access through their involvement in two schemes: nurse-led triage and telephone consultations in general practice and nurse practitioner-led care in general practice. A study by Lattimer et al. (1998) provided evidence that nurses can manage a high proportion of out-of-hours primary care calls safely and effectively. Pinnock et al. (cited in Chapman et al., 2004, p377) assessed the impact of nurse-led telephone consultations for routine asthma medication review and found telephone consultations used in this way to be significantly time saving and without any differential in adverse outcomes compared with face-to-face care. According to them there is some evidence that nurse-led care for minor conditions is as safe and effective as care by physicians; that is, resulting in similar clinical outcomes. Shum et al. (2000), Venning et al. (2000) and Horrocs et al. (2002) assert that there is

evidence that nurses give longer consultations and carry out more tests; however, no difference has been found in referral rates to secondary care between physicians and nurse practitioners.

This specific literature supports the rising role of the nurse in promoting and facilitating access to services; and makes implicit associations with the concept of quality nursing care. Therefore, the views expressed by the nurses do not seem to be supported by the literature and contradicted to those of the patients and advocates in this study. A female staff nurse gave a possible answer why such disparity exists “[...] *It is my guess that they speak about quality in a more holistic way [...]*” (SNI-5). These findings suggest that the patients made the link to accessibility because they tend to hold a whole picture of their health which does not separate the parts (e.g. nursing care) from the whole. They considered that since the health care professionals share and work towards the same task, caring for the patient, they considered that the quality of the care should include the actions from all health care professionals and not only the nurses who merely provide an aspect of the care. “*The actions of all health care professionals involved in the care of the patient are included [...]*” (SNI-5). Further the nurses claimed that the patients are not aware of the borderlines of nursing, and what nurses can influence through their practice. They also highlighted that issues of power prevent nurses from being involved in access and availability matters. “*Their difficulty to separate where nursing care begins and where nurses can influence something with their work*” (SNI-5). As it was revealed through the narratives nurses’ focus on the nursing-specific issues indicated a lack of joined up thinking which constitutes the basis for partnerships. These partnerships can be formed either between nurses and patients or between nurses and other health care professionals, and lack of this joined up thinking poses a threat to these partnerships.

Therefore, the findings raise a question here, who is right and who is wrong. Are the nurses correct or are the patients’ perceptions and connections telling us something about nursing which the nurses themselves can not see, or perhaps patients feel that nurses should have the power to influence decisions pertaining access and availability

issues? The aim of this study was to highlight the meanings that are attributed to quality of nursing care by the patients, advocates and nurses and not why these are attributed. However, the findings provided an implicit answer to this question. The patients spend most of their time in the hospital near nurses and appear to feel safe around them often developing close relationships with them. Therefore, in this safe and trustworthy environment they can express their problems they have in accessing the services and request the nurses to address or influence the decisions that will eventually solve the problem. I believe that the patients have based their opinions in beliefs rather than on facts about who controls access issues. It appears that the patient overestimated the abilities or the range of control of the nurse. Alternatively, it is my belief that nurses hold a more realistic view of the issue. A key word that has been raised in the narratives was the word “power”. The nursing division in the MoH does not have the power to influence policy such as access and availability, but rather its mission is more advocating in nature. This advocating role of the nurses has been raised by the informants “[...] identifies such problems or the patient himself expresses such problems... she must take these concerns and problems to the management committee...so that actions can be taken [...]” (F-45, WMI-I4). Therefore, it is not a matter that who is right and who is wrong but it is rather a matter of different perspectives.

Being cared for by nurses who effectively communicate with them and their families and provide emotional support¹⁰²

Naïve Reading

According to the naïve understanding the patients and their advocates referred to quality nursing care as an ability to communicate with their nurses for personal issues and issues related to their health and expected to receive emotional support by them. They expressed the importance of good communication with the nurses and acknowledged that it consists of a fundamental element of the quality nursing care. Informants in their

¹⁰² In Greek – *Na se frontizoun nosilestes pou mporoun na epikoinonoun apotelesmatika mazi sou kai na se stirizoun sunesthimatika*. Να σε φροντίζουν νοσηλευτές που μπορούν να επικοινωνούν αποτελεσματικά μαζί σου και να σε στηρίζουν συναισθηματικά.

conceptualisations of this concept have described it in terms not only as simple exchange of information with the nurses and other health care professionals but also as conveying feelings and concerns. Informants reported on poor communication between nurses and patients. The reasons included the lack of time, the provision of insufficient information to patients, and the beliefs held by the nurses in relation to patients' ability to understand aspects of their illness.

Structural Explication¹⁰³

The structural explication that followed seems to verify the initial understanding gained from reading the text as a whole. What has been verified is the belief of the patients and advocates that communication with the nurses consists of an essential part of quality nursing care. Through the structural explication the following themes were formulated:

A. Communication although a constituent of quality nursing care remains hermetic

The informants acknowledged that communication with professional carers holds a central place in quality nursing care and it's also being considered as a means to value quality nursing care. "*Quality nursing care is...includes many different things but for me being able to communicate with my carers is perhaps the most important*" (F-57, PI-1). The informants used metaphors in order to describe how the communication should be between patient-nurse; hence, they described it as being "healthy". In their descriptions of a healthy communication, informants asserted that the provision of adequate time by the nurses, the avoidance of strict "communication agendas" and free from the belief that most patients are unable to understand technical terms. Analysing these three prerequisites individually, it seems that an aspect of quality nursing care relies on the nurses' attitudes. Particularly, here I am referring to the belief which several nurses hold; that patients are unable to understand technical, medical or nursing terms and this is used as a justification why they avoid communicating with the patients. However, cancer being a chronic disease and with the new treatments and medications this means that many patients will have a prolonged experience living and learning about the disease.

¹⁰³ See appendix C-Table 11.

Moreover, the Greek-Cypriots are becoming more educated, as I have discussed earlier, which means that they have an increased ability to understand information given to them by nurses. Therefore, the claim made by the nurses that patients are not able to value the information given to them, is only an *essoin*. The lack of time that was raised by the patients as a barrier for healthy communication is perhaps connected with the poor nurse staffing levels in cancer care departments.

B. Communication tends to be one-sided

Patients claim that nurses tend to hear what the patients tell them; however they rarely listen to them. As a result communication is many times one-sided. “[...] *nurses rarely listen to us...they can hear us speaking to them but they do not necessarily listen to us, thus the communication tends to be one-sided*” (F-58, PI-23). What has really been communicated on these occasions, is what the nurse had to say and not what the patient had to say. This means that the patient is not given the opportunity to express his/her worries, needs, and queries about his/her treatment and care or even a more personal problem. In this negative communication environment the patients and their families do not feel comfortable to express their feelings and thoughts about the disease or more personal issues. Instead, because of the attitude of the nurses, they communicate at a more superficial level, being selective in what conversations they engaged in with their patients and implementing avoidance for those cases when they do not want to engage in.

C. Good communication skills are valued by the patient and the family as a means to improve care.

The informants in the narratives highlighted the possession of good communication skills by the nurses and stressed how these can be valued in clinical practice and particularly for the emotional support of the patient. “[...] *when I am “down” or feeling “blue” the nurses can pick up these silent signals and act upon it*” (M-57, PI-14). Furthermore, good communication skills allow the nurses to involve the family in the emotional support of the patient. Informants referred both to verbal and non-verbal

communications skills emphasising that these are equally important to quality nursing care. These allow the nurse not only to appraise but also to identify unspoken needs of the patient, which are sometimes more important and perhaps more difficult for the patient to express. The difficulty in externalising these needs appears to be the cause of the insufficient or superficial communication that the patient encounters in the department.

D. Through communication nurses can better understand the patients and the family.

This theme complements the previous one. The advocates repeatedly commented on the value of good communication between nurse and patient and between nurse and family, asserting that communication and quality nursing care are closely related and that the latter can not be achieved without the former. “[Without communication] *he/she [nurse] can only care for the patient in a “raw” and “cold” manner, which of course will reflect on its quality*” (FG with PA). Informants assert that good communication allows the patient to share with the nurse his/her world of experiences and feelings and hence receive emotional and physical support. The nurse can better understand the patient and based on this, to tailor the care to suit his/her individual characteristics. The patient can better know the nurse which will promote good communication with him/her. This relationship enables the patient to feel more comfortable in expressing his/her feelings and reaching out to the nurse. Establishing good communication with the family is also an important aspect that nurses need to take into consideration when caring for the patient, as the family can also support the patient emotionally and physically.

Comprehensive Understanding

The reflection on the naïve understanding, the structural explication, and my pre-understandings as well as the context of the study, the research questions and the literature has helped me to reach at a comprehensive understanding. It is evident in the narratives that, patients and their advocates consider communication between nurses and patients and their families as an important aspect of the care, which recurrently has been

related to quality nursing care. The magnitude of its importance has been raised by the advocates who claimed, that quality nursing care can only be achieved through good communication.

According to my pre-understanding, I anticipated the informants raising this issue as an aspect of quality nursing care. Being a nurse myself and having experience of working with patients with cancer and their families I considered good communication between nurse-patient and nurse-family as the cornerstone for entering the world of the patient and vice versa. This enables the nurse to offer a more personalised and humanistic approach to care and also the patients feel they are being cared for in an environment of understanding where they feel comfortable to speak openly to the nurses. However, what I did not expect was the dissatisfaction uttered by the patients and the advocates in relation to the low quality of the nurse-patient communication.

In order to ensure that the informants in the narratives shared the same conceptualisation of the term “communication” I considered it necessary to obtain their perspectives through the narratives. They held a wider understanding of the concept which extended beyond the simple provision of information to conveying of emotions, thoughts and worries, valuing therefore a therapeutic form of communication. A minority of informants understood the concept simply as receiving information from the nurses. Their responses coincided with some conceptualisations found in the literature which is presented below.

“Communication” according to Austin (1970) and Grice (1975) is fundamentally understood as a matter of someone successfully conveying thoughts, feelings or other mental states or events to an audience. Furthermore, it is presupposed that thoughts and feelings are not accessible to audiences directly; they have to be represented in verbal or nonverbal behaviour. Knowledge of, or warranted belief about, the thoughts or feelings of another person must therefore be based on interpretation (Davidson 1984). Haber et al. (1992) assert that communication is a “continuous circular process by which information, such as ideas and feelings, is transmitted between people and their

environment. It involves symbols, such as written words, and spoken language” (p132). According to the same authors the ultimate goal of communication is to understand and be understood. Papadopoulos and Lee (2004) assert that communication extends beyond conveying information to conveying emotional and social support. This study has emphasised the importance of emotional and social support for patients with cancer and therefore, this is an additional reason why the aspect of communication is an integral part of the care. The potential for health care professionals to convey emotional support to patients has also been highlighted by Slevin et al. (1996).

When it comes to communication and particularly good or bad patient-nurse communication, informants in my study expressed the opinion that there are problems. Generalisations however, should be avoided since with some nurses good communication exists. This variation among informants might have different interpretations. One interpretation is that the nurses that cared for the patients had different training, with some having specialised training on cancer care. Therefore, these nurses were more likely to be able to communicate better with the patients and also to support them emotionally. Another interpretation is that nurses with no prior training on cancer issues, had clinical experience from working with patients with cancer which varied. Another interpretation that may be attributed is that the nurses despite being trained or not they have to deal with their feelings about having to confront death and dying on a daily basis. Coming from a culture where such issues are considered taboo and opportunities to discuss such issues are rare, nurses find themselves struggling by themselves to cope with the painful aspects of their work. The difficulties in coping with their feelings and engaging in such discussions also seems to reflect their ability as nurses to communicate with the patients. Nevertheless, some nurses were experienced in caring for patients with cancer which allowed them to develop their communication skills and better communicate such issues with their patients unlike the nurses with limited or no clinical experience in cancer care departments.

Therefore in spite of the importance that informants placed on communication, they believe that in clinical practice it remains persistently one-sided and hermetic, making it

difficult to be informed about their health and feeling comfortable to express their unvoiced needs, worries, and feelings. The ethnohistory of Cyprus possesses a possible interpretation of why communication between health care professionals and patients remains problematic. Long-standing beliefs held by some health care professionals that when it comes to care they are the ones to make all the decisions including how and when to communicate with the patient, are the source of some of the communicating problems reported in this study by patients and their advocates. Sowden et al. (2001) assert that most common complaints made by patients with cancer are about poor communication and inadequate information. A major problem that patients reported on in my study was the fact that many nurses in the process of communicating information to the patients, failed to tailor this information to suit patient's educational background and his/her general level of comprehension. Earlier, Harris (1998) concluded to the same findings with additional emphasis on the patients' cultural orientation, in those cases that the patients came from different cultural backgrounds.

Patients and advocates assert that nurses need to improve and further develop their communication skills in order to promote effective communication which is not limited to information giving, but also includes emotional support and comforting the patient. These findings coincide with those of Kruijver et al. (2000) who performed a literature review in relation to the nurse-patient communication in cancer care. They assert that "emphasis is placed on the affective side, in which facilitating behaviours such as empathy, touch, comforting and supporting are considered essential in caring for patients with cancer" (p20). Further studies in this review, demonstrated that communication in cancer care is complicated by such emotionally burdened issues as, the consequences associated with the life-threatening character of the disease and the far-reaching consequences of the medical treatment. This may lead according to Kruijver et al. (2000, p30) in barriers to effective communication between patients and nurses. It is therefore important that nurses working with patients with cancer are supported by the hospital to develop their communication skills through continuing education programs. The need for communication training is evident in the literature (Davidson and Mills 2005). Jarrett and Payne (1995) selectively reviewed the literature on nurse-patient communication.

They found that previous research studies came to the conclusion that the quality and quantity of nurse-patient communication was brief and superficial (p73). According to the same review, nurses appeared to “be controlling and restricting the course and topics of conversation with patients” (p77), a finding that has also been highlighted by my study, since the informant commented that the nurses tend to use “communication agendas” based on which they choose what and what not to discuss with their patients and their families. The need for training the nurses in order to further develop their communication skills has been recognised by the researchers and has been advocated as a possible solution (Ashmore and Banks 2004; Jarrett and Payne 1995). Davidson and Mills (2005) performed a quantitative study in order to investigate patients’ with cancer satisfaction with communication, information and quality of care. They asserted that measures need to be taken in order to promote effective communication since effective communication between the patient and his/her care can determine long-term psychosocial outcomes in patients with cancer. They also stressed the importance that patient-professional communication needs to be tailored to meet individual needs, an aspect which has also been stressed by the informants in my study.

Through communication nurses can better understand the patients and therefore better care for them. Communication with the patient during hospitalisation and within the multidisciplinary cancer team is an important and sometimes overlooked component of optimal and efficient cancer care (Tattersall and Ellis 1998). Gunther and Alligood (2002) assert that, communication promotes individualised patient care, which requires more than just the provision of empirical information. It is required that the nurse knows the patient, so that she/he can apply information to the patient’s unique life situation. Gunther and Alligood (2002) assert that knowing the patient constitutes “an essential antecedent for the provision of good quality care” (p356). These findings according to Mok and Chiu (2004, p481) further support the view of May (1995) and Luker et al. (2000) that it is only through knowing a patient, that nurses can provide care that fulfils the specific needs of that patient. Knowing a patient through effective communication allows nurses to more truly understand patients and their world as if they were inside it. One must be able to understand the other person’s needs and respond properly to them.

Knowing the patient, however, often means knowing the family as well. As informants pointed out in my study, family plays an important role to care and nurses need to communicate with them as well and involve them in the care. The difficulties in communicating with family members and the importance of communicating with families have been stressed in the literature. Davis et al. (2003) assert that poor communication with health professionals creates the most distress for families of patients with cancer. Difficulties communicating with families also have been identified as potentially stressful for nurses (p337). Curtis et al. (2001) assert that understanding and improving communication about end-of-life care between clinicians and families in the ICU is an important focus for improving the quality of care in the ICU. Because excellent end-of-life care is an important part of high-quality intensive care, ICU clinicians should approach the family with the same care and planning that they approach other ICU procedures.

A recent hermeneutic phenomenological study McCabe (2004) concluded that in contrast to the literature that suggests that nurses are not good at communicating with patients; nurses can communicate well with patients when they use a patient-centred approach. However, the researcher emphasised the fact that health care organisations do not appear to value or recognise the importance of nurses using a patient-centre approach when communicating with patients to ensure the delivery of quality patient care.

Being empowered by nurses through information giving¹⁰⁴

In the literature communication and provision of information are often discussed collectively, a feature that was observed in this study as well. These topics were closely interrelated according to the informants and that is why I decided to report on them consecutively. Many patients considered that good communication exists when the nurses provided (on request or not) information about their health problem (i.e.

¹⁰⁴ In Greek – *Endunamosi ton asthenon apo tous nosileftes meso tis parochis pliroforion-* Ενδυνάμωση των ασθενών από τους νοσηλευτές μέσω της παροχής πληροφοριών

diagnostic tests, results, medication, course of the disease) and alternatively they believed that the communication was bad when they were deprived of such information.

Naïve Reading

As with the importance of good communication to the quality of nursing care, the provision of information was considered as equally important. Patients with cancer believe that they are not receiving sufficient information from the nurses in relation to their care. Few nurses offer more information than others indicating the lack of an organisational policy for providing information. On the same issue, patients implied that there were issues of power between the nurse-physician relationships that reflected on the nurse's ability to provide information. The majority of the patients appear to trust the nurse to provide them with all the information they need. Finally, providing information was also found to relate to the ability of the patients to actively participate in decisions about their treatment and care.

A naïve guess of the meaning of quality nursing care, as disclosed through the patients and advocates narratives, is that quality nursing care is interrelated with the adequate informing of the patient on every aspect of his/her care. Weakness to adequately inform the patients however appears to be a complicated issue involving issues of the hospital's organisational culture.

Structural Explication¹⁰⁵

The patients and the advocates asserted that providing information to patients is a constituent of quality nursing care. However, they claimed that in real life there are barriers to receiving adequate information from the nurses. Through structural explication the following themes were formulated as part of the main theme:

A. Proximity and trust enables information sharing.

¹⁰⁵ See appendix C-Table 12.

The informants acknowledged the importance of providing information to the patient and related this aspect of the care with the provision of quality nursing care. The importance of information giving has also been linked with another aspect of the care that of participation in shared decision-making which has also been found to contribute to the provision of quality nursing care. The patients speak about a “special” relationship that they have with the nurses due to their continuous contact with them which in turn leads to the growth of trust. *“Spending 24 hours a day around nurses allows me to have a ‘special’ relationship and a better communication with them. I can trust them [...]”* (F-58, P1-11). In this trusting environment, communicating with the nurses becomes easier as well as the exchange of information in relation to the care and treatment.

B. Organisational culture and lack of policy.

The informants reported on issues related to the organisational culture and policy issues considering these as the main barriers for being adequately informed by the nurses. When referring to the culture of an organisation I mean the amalgamation of the values and beliefs of the people (i.e. nurses and physicians) in the hospital. Along with the scarcity of policies that regulate this issue, the hospital discourages nurses from informing the patients. In clinical practice however, nurses discretely give the patients certain information regarding their care. It appears that patients and nurses have developed a trusting relationship that allows an exchange of information during the provision of care. Information gives the physician power over the patient which he/she is reluctant to share with the nurses and due to this fact they negatively face the possibility of nurses informing the patients. What the informants are referring to here is another issue, that of power, which has also been identified as a barrier for the participation of patients in their own care through shared-decision making. Another aspect of this issue is the fact that nurses often in clinical practice avoid giving the patient information, in order to avoid conflict with the physicians in those cases that the nurse has a different view of the care. However, the possibility that nurses choose not to inform the patients in order to avoid assuming the responsibility, they prefer the rather simple solution to the problem *“your physician will inform you on your situation”*.

C. Nurses' beliefs and attitudes.

The informants claim that nurses (and physicians) hold certain negative assumptions about giving information to patients. In clinical practice they tend to avoid providing them with the information they need based on the belief that patients are not interested or able to understand disease related information. "*Some members of the staff do not take you into their confidence and hardly give you any meaningful information [...]*" (F-21, PI-6). However, the difficulty the patients acknowledged in understanding the information given to them might be grounded in the nurses' failure to tailor the information to suit patient's educational background, cultural orientation, and general level of comprehension. Consequently, patients are reluctant to request information that they find it difficult to understand, a behaviour that might be mistakenly interpreted by the nurses as unconcern for information. However, this assumption should not be generalised to the whole of the patients since through the narratives it was highlighted that there is an increasing number of patients requesting to be fully informed about their care, treatment and health and wanting to actively participate. Therefore, the changing behaviour on behalf of the patients overrules this worn-out belief held by nurses and physicians. The limited information patients receive from physicians forces them to frequently request more information from the nurses, who seem to trust and feel closer to them, in order to better understand issues related to their care and treatment.

Comprehensive Understanding

The structural explication confirmed the naïve reading of quality nursing care being understood by the informants as receiving adequate information from the nurses. This attribute of the care appeared to be more important for patients that were relatively recently diagnosed with cancer. A female patient, aged 58, asserted that "*The nurses need to understand that I do not know everything about my illness [...]* I was diagnosed in November (6 months prior data collection) and I am worried on what might happen to me [...] the nurses need to have patience and inform me based on what I need to know". Similarly a male patient which was also recently diagnosed, aged 66, asserted that "*It is so stressful having something wrong with your health and know very little about it [...]* I

need reassurance and support and the nurses can offer these through their knowledge and practice". Their recent journey in the cancer experience meant that these patients and their families had more queries about the disease, possible treatments to choose from, worries about prognosis and perhaps more difficulties in accepting the fact they had cancer and all its negative connotations. Another possible interpretation for seeking to be informed is the feeling of "loss of control" that these patients may experience in such an early stage of their illness. These concerns offer a possible interpretation on the patients' desire to be adequately informed in relation to cancer and their care. Regardless of the patient's willingness to be informed, in the narratives it was revealed that the lack of information might be attributed to another reason. As the informants have commented, there are times where the patient might be confronted with nurses with limited knowledge or with nurses who are afraid to disclose any information to the patient. As a result their informational needs can remain unsatisfied and therefore the patients seek information from elsewhere (e.g. physicians).

The informants asserted that generally they did not receive enough information during hospitalisation. Few patients asserted that the information they received was sometimes vague and misleading failing to give an objective picture of their health status and how serious their problems really were. This is grounded in the beliefs held by the nurses and other healthcare professionals that patients are incapable of handling disease related information provided to them. These beliefs are inherent in the ethnohistoric background of the Greek-Cypriot nurses and physicians. Their dominating influence in health related issues is a determinant factor as to the nature of the communication that is adopted in clinical practice as well as to the nature of the information given to patients and their families. Therefore, communication and information giving is not decided based on the patient's preferences but rather is left to the nurse's and physician's eclectic power to choose what is appropriate for the patient based on their own understanding of what is best for him/her. A wide body of literature supports the views expressed by the patients, that healthcare professionals might underestimate their desire for and ability to cope with health related information. This assumption might lead to the provision of limited

information to patients with cancer and their families (Tamburini et al. 2003; Sowden et al. 2001; Smith 2000).

Many patients related the provision of information with the presence or absence of good communication with the nurses. Indirectly patients expressed the opinion that they seem to communicate better with the nurses rather than the physicians. When this issue was raised in the focus groups there was an agreement among the patients that this was indeed a fact. In order to justify their opinion the informants claimed that “*the physician is around only for a few minutes during the day and almost never at night*” (FG-1), “*the physician during the round in the morning rarely answers to our questions, because we have so many and there is so little time to ask them, therefore is necessary to ask the first question that troubles us at the moment, thank God we have the nurses to fill in the gaps [...]*” (FG-2).

With paternalism becoming more and more outdated approach to the care of the patient, and with the patients becoming more informed and willing to actively participate in decisions pertaining their care, nursing and other health care professionals need to better and adequately inform their patients in order to promote their participation, an aspect of the care that promotes patient satisfaction. Cox et al. (2006) assert that in order to enable patients participate in decision in relation to their own care it is important to establish an effective communication with the patients in order to provide them with the necessary information. Mallinger et al. (cited by Cox et al. 2006, p264) assert that patients are depended on the information given to them by health care professionals and “it is possible that providing patients with adequate information not only permits informed decision-making but also improves coping and leads to better psychological health”.

The findings of this study highlighted the fact that the majority of patients want as much information as possible about their diagnosis, prognosis, treatment and care and feel more empowered when they are informed. These findings seem to concur with the findings of Bakker et al. (cited by Trudel et al. 2004, p7) who studied the perspectives of women with breast cancer in relation to the provision of information during

chemotherapy and another study by Jenkins et al (cited by Cox et al. 2006, p264) who investigated the informational needs of patients with cancer in the UK. However, contrary to their needs, patients with cancer do not always receive sufficient information from nurses and other health care professionals. These findings coincide with a growing body of literature (Voogt et al. 2005; Sainio and Eriksson 2003). A study by Davidson and Mills (2005) concluded that the cancer site appear to influence the satisfaction with the information they received from their health care professionals. However, this finding was not confirmed by my study. Sainio and Eriksson (2003) in a quantitative study with 273 patients with cancer investigated how much information do patients get from their nurses and physicians. The analysis of the data showed that the patients were not adequately informed about the prognosis, the alternatives of treatment and the effects of cancer or treatment. In a similar study with 128 patients diagnosed with incurable cancer, Voogt et al. (2005) investigated what these patients were informed about. Whilst the patients reported that they received adequate information on disease-specific issues they acknowledged that more information is needed with emphasis on psychosocial care. With the evidence showing that it is not easy for the patients with cancer to be engaged in discussions in relation to such issues, it is up to the nurse and the physician to encourage the patients to open up in relation to this aspect of the care (Bakker et al. cited by Trudel et al. 2004, p7).

Nurses' response to patients perceived meaning of quality nursing care, as being cared for by nurses who effectively communicate with them and their families and provide emotional support and being empowered by nurses through information giving .

Naïve Reading

The text showed that the meaning of quality nursing care according to the nurses was based on their experiences of communicating and informing the patients which appear to coincide with what the patients and advocates have stated above. Problems arising from the nurse's inability to effectively communicate information, feelings, concerns,

thoughts were acknowledged and are considered as obstacles to communication with the patient. They focused on the lack of training during nursing education in relation to the development of their communication skills. As a result, frequently they found themselves in a situation where they failed to establish effective communication with the patients and their families. In relation to informing the patients, nurses admitted that frequently they underestimated patients' desire for and ability to cope with information, reasons which influenced their eagerness to inform the patients. The lack of protocols on how to inform the patients or what to include in the information was the major and most frequent reported factor why nurses avoided the provision of any disease related information.

Field Note: What I have noticed during the narratives was the surprise of the nurses of the patients' perspectives on quality nursing care. It seemed that they did not expect the patients to get into so much detail in relation to their care. Their dissatisfaction with the ability to effectively communicate with and receive information from the nurses also came as a surprise to them. They anticipated that the patients would be more satisfied with this aspect of their care.

Structural Explication¹⁰⁶

Through the narratives, the nurses expressed their belief that the concept of "quality nursing care" relates to issues of communication and provision of information to patients. The majority of the nurses supported the findings from the patients and advocates narratives, highlighting the importance of effective communication and provision of adequate information to patients. The nurses acknowledged that there can be problems with communicating effectively with the patients. Simultaneously, they identified that the main barriers for adequately informing the patients remain the lack of policy and their cancer related beliefs.

¹⁰⁶ See appendix C-Table 13

A. Lack of formal communication skills education which is considered by nurses a burdensome aspect of the care.

The nurses whilst acknowledging the presence of problems when communicating with patients claimed that these are entrenched in the nursing educational system currently in place in Cyprus. “[...] *We have not received any formal or any other training on how to develop our communication skills, therefore I solely rely on my experience*” (M-35, WMI-12). Their nursing training does not address issues related to communication and specifically the development of appropriate communication skills. This dearth is worsening by the fact that the nurses are rarely given any opportunities to participate in educational seminars or courses on enhancing their communication skills due to the insufficient staffing of the cancer care departments and the lack of time. As a result, nurses heavily rely on their experiences to improve their communication skills. Reflecting on these experiences, they confessed that often found themselves in situations where they failed to acknowledge non-vocal (silent) messages sent by the patients something that negatively influenced the provided nursing care. They further commented on occasions that they avoided some patients due to their inability to communicate with them. Therefore, communicating with the patients appeared to be a burdensome experience for most of the nurses.

B. Nurses’ beliefs on informing the patients.

Through the narratives the nurses’ responses revealed that their actions were guided by certain beliefs in relation to informing the patients. “[...] *Providing adequate information to patients can be psychologically harmful for them*” (F-31, SNI-7). Explicitly, these beliefs related to the ability of the patients to cope with such information often leading to poor understanding or misunderstanding of the information and their (lack of) readiness to be informed. These beliefs appear to derive from the nurses’ cultural background as well as the collectivistic character of the Greek-Cypriot family. Specifically, this collective character operates as a “protective” and “filtering” mechanism when it comes to informing the patient. This becomes more apparent when vulnerable groups of patients are involved. It is common that nurses, physicians and

other health care professionals to be urged by the family not to reveal to the patient the whole truth about his/her health. Greek-Cypriot nurses often hold analogous beliefs on this matter. As a result, it is acceptable that much information is hidden from the patient, sometimes even his/her diagnosis, often due to the fear provoked by cancer and the psychological effect that this might have on the patient as this is perceived by the family.

C. Policy restraints to informing the patients.

The nurses feel disempowered from the lack of policy on informing the patients. As a result they are not allowed to give specific information to the patient in relation to their health. *“The current policy or protocols do not allow as giving any specific or detailed information to the patient, something that only the physician is allowed to do”* (M-50, WMI-13). On the contrary, the physicians are claiming monopoly on informing the patients, something that seems to relate to issues of power and control. Further than policy issues the nurses reported on the need for protocols in clinical practice which will demonstrate how and what to inform the patients about. What the nurses appeared to agree upon was the burden they experienced from those incidents where the patient required information from the nurse. They felt ill-equipped to deal with the situation which in turn caused them emotional burden.

Comprehensive Understanding

There appears to be a consensus on the meaning of quality of nursing care as communicating effectively with and informing the patients. The literature also seems to point to this direction. Mullen (1997) for example, asserts that patients, who are well informed about prognosis and treatment options, are more likely to adhere to treatments and have better health outcomes. Therefore, more time should be spent assessing not only the best medication for a particular condition but also the best for a particular individual with a certain lifestyle and preferences. The concept of concordance suggests frank exchange of information, negotiation, and a spirit of cooperation. *“Patients and practitioners are more likely to have known one another for longer, dispensing is less impersonal, and ancillary personnel are available for follow up”* (Mullen 1997, p691).

Coulter (2002) referring to the British NHS, asserts that the provision of information to and involvement of the patient is at the heart of the patient centred approach to health care. The quality of clinical communication has been linked to positive health outcomes.

Nurses also seem to share the views expressed by the patients and advocates, concerning the lack of effective communication between patients and nurses and the non provision of adequate and specific information related to their disease. This is perceived as an integral part of a quality nursing care. Meredith et al. (1996) assert that not being told what is wrong with them is the most common complaint that patients make about the health care professionals. Similarly, Sowden et al. (2001) referring to patients with cancer assert that their most common complaints are about poor communication and inadequate information. Nurses in my study appeared to feel ill-equipped to handle discussions with their patients about life and death issues and may be reluctant to engage in open communication with them about a life threatening disease. This difficulty acknowledged by the nurses might also have its origins in the fact that cancer in Cyprus is considered as a taboo topic, mainly due to its life-threatening nature. Greek-Cypriots nurses as a product of their society also face difficulties in openly communicating about cancer. So immense is the fear that cancer provokes to the Greek-Cypriots that the word "cancer" is "forbidden" on the ward and in discussions with the patients and their families. There is a fear that even saying the word will cause it to happen. The anxiety provoked will according to the nurses' belief make it difficult and even impossible to fight the disease.

Nurses believe that the problems they experienced and reported by the patients are generated mainly by factors which are beyond their control such as the nursing school's¹⁰⁷ education policy the absence of protocols which will define what and how to provide information to the patients, the MoH policy on informing the patients and finally time constrains issues. The latter can be the result of the nursing shortage and the increased workload in the cancer care department which limits the available time that the

¹⁰⁷ The Nursing School in Cyprus is the responsible body to decide what to include and what to exclude in the nursing curricula

nurse can spend with each patient (Panayiotou 2006; Turimou 2005; Karakatsani 2005a; Karakatsani 2005b). Therefore, there is often insufficient time to fully explain the condition, treatment choices, medications or any other aspect of the treatment and care of the patient and the family. The findings from three consecutively surveys by Buerhaus et al. (2007) showed that the nursing shortage has negatively impacted communication, nurse-patient relationships, and timeliness of care and overall efficiency; therefore confirming the findings of my study.

Nurses also acknowledged their share of responsibility for ineffective communication with the patient. As they report in the narratives, communication is a process that takes two and as a result at some cases they are responsible for failing to effectively communicate with the patient. Faulkner (1998) supports this view, asserting that effective communication depends not only on the professionals but also on patients and family. According to Faulkner (1998) when the language used by health care professionals is ambivalent, then the patient may jump into conclusions or leading to misunderstand what is actually implied. Furthermore, it should also be taken into consideration by health care professionals the fact that family and patient may have different informational needs. "This may lead to health professionals feeling as though they are "pig in the middle" as they try to meet the needs of their patient and those of relatives" (Faulkner 1998, p130).

Meredith et al. (1996) explored the information needs of patients with cancer in west Scotland. The results indicate that patients interviewed wanted more information about their disease, whether their disease was cancer (96%), their chance of cure (91%), and the possible side effects of treatment (94%). However, most of the patients not only wanted to know their diagnosis but also wanted to be told plainly if they had a cancer. Therefore, some of the views expressed or implied in this study by the Greek-Cypriots nurses that elderly patients do not want to be informed are overruled by the Meredith et al. study. The researchers assert that most of the elderly patients (age over 65) and most of those receiving palliative treatment wanted to know their diagnosis. According to Meredith et al. (1996, p725) this is a relatively recent trend as "about half of a group of

patients with inoperable lung cancer who were interviewed before 1981 did not ask for a diagnosis when given the opportunity”.

Some of the nurses commended that patients should be deprived of certain information related to their disease, treatment, prognosis and lab results for their own benefit. This is not a surprising or recent trend in the reality of the Cypriot culture. As discussed above the fear and distress provoked by the word “cancer” and its negative connotations urges the nurses to act as colluders with the family giving its assent. They believe that the patient already has a difficult battle to win without knowing that he/she suffers from cancer, that they do not wish to burden the patient with additional emotional distress and anxiety. As part of their role as “colluders”, nurses often intentionally conceal important information from the patient and inform his/her family member instead. As Meredith et al. (1996) pointed out in their paper “this well intentioned omission is due to the nurses’ (and physicians’) feeling that knowledge of the diagnosis will depress and alarm patients and will impair their quality of life” (p725). The patient’s family held similar beliefs in Cyprus, mainly due to their belief that this way they protect their loved ones from further distress. The word “cancer” in Cyprus has been “connected” with death and therefore appears to cause stress for both health professionals and patients, and these may be some of the reasons why physicians and nurses avoid communicating bad news. Faulkner (1998) comments that collusion is generally “an act of love or a need to protect another from pain” (p131). Reflecting on the reality in Cyprus, it is common that the family members of the patient or other acting as “colluders” claim that the reason for their behaviour lies in the fact that there in a better position to know the patient and what he/she needs. “They may further argue that telling the truth would take away hope. Once reality has been accepted, hope can be more meaningful and based on short term, achievable goals” (Faulkner 1998, p131). This claim is accord with Helft (2005) who asserts that collusion may be used to facilitate the preservation of hope in an honest way. According to Meredith et al. (1996) some think that communicating with patients about their diagnosis and prognosis would cause a state of depression. Physicians and nurses have only limited time with each patient, and communication may often have a lower priority. In spite of what colluders or health care professionals believe about hiding the

truth from the patient, this may lead to adverse results such as anxiety, uncertainty or even create over ambition about the outcomes of the care which in turn may lead to dissatisfaction and disappointment. Evidently “the level of psychological distress in patients with serious disease is less when they think that they have received adequate information” (Fallowfield et al. cited by Meredith et al. 1996, p726).

Nurses claimed in the narratives that during their nursing education their learning needs were not met in relation to effective communication skills and informing patients. Based on the image that physicians hold in the Cypriot health care context, as this was analysed in the ethnohistory of Cyprus¹⁰⁸, nurses appear to be up against the doctrine promoted by physicians that “informing the patient is the physician’s job and not the nurse’s”. Physicians hold a powerful position in the Cyprus HCS, managing the hospitals and making policy which enabled them to introduce and maintain this doctrine in the hospitals. The nursing profession has also long suffered from public stereotyping and from being closely associated with femininity and powerlessness. As a result nursing’s identity as a profession has been questioned and challenged by the public leading to nursing not being valued as a profession.

Regardless, nurses are expected to become more effective in communicating with the patient, mainly through experiential learning and participating in lifelong learning seminars where these are provided. It may also be the case that nurses lack knowledge in certain treatment options and their effects, and therefore be unable to adequately inform the patient. As part of their professional practice and because of the bedside delivery of the care they are more likely to face questions in relation to these issues. Cancer is a life-threatening disease which causes the patient anxiety and as a result the patient is more likely to have several questions about his/her condition, the prognosis and the treatments and will need constant reassurance. The lack of support that nurses face has been stressed by Sowden et al. (2001) who assert that health professionals most likely need support if patients’ information needs are to be met. Sowden et al. (2001) identified the learning needs of healthcare professionals including nurses in fulfilling the information needs of patients. They assert that informing the patient needs to gain a higher priority;

¹⁰⁸ Also see chapter 4

the professional needs to retrieve the patient's needs; understanding the emotional aspects of learning; helping patients to understand; learning from the patient; and knowing about information sources (p195). In Cyprus, ensuring that such needs are addressed in both undergraduate and continuing professional education will help in meeting patients' information needs and achieving the goals of future government policy with the introduction of the NHIS. As well as challenges to the health professional in meeting peoples' information needs, organisational challenges have also been recognised and recommendations made by Jones et al. (cited by Sowden et al. 2001, p195). These recommendations include: "treating patients' information needs as a core activity; ensuring adequate funding, space and time devoted to patient information; producing, implementing and reviewing guidelines on patient information and auditing methods of working" (Jones et al. cited by Sowden et al. 2001, p195). Furthermore, Tattersall and Ellis (1998) assert that "teaching communication skills has only recently been recognised as important in the training of medical students and more senior medical staff" (p1891). In the process of providing information to patients, the nurse's or physician's attitude is important; a health professional who has developed communication skills and knows approaches for informing can give desired messages that give the amount of information that the patient wants and when the patient is ready. The subject of providing information and especially "truth telling" may vary from country to country and culture to culture, therefore the cultural norms of each culture need to be considered prior to informing the patient. The reason is reflected in different ethnic roots, religious beliefs, cultural differences and legal regulations (Surbone 2006; Mystadikou 2004). Tattersall and Ellis (1998) assert that various groups dealing with patients and especially patients with cancer have prepared guidelines on "breaking bad news" and "preparing patients for investigations". What is notable about these recommendations is that they advocate for "eliciting patients' expectations and their information preferences and needs" (p1891). However, achieving these requires the nurse to know the patient. Mok and Chiu (2004) emphasised the importance of knowing patients and being involved with them. This allows the development of patient-nurse relationship, which includes satisfying the needs of individualised patients and being exposed to and resolving psychological problems. Patients', nurses' and advocates'

narratives described the investment of effort by nurses into knowing patients. This knowing enabled nurses to obtain an objective view of patients' total needs including information needs.

In the narratives, there were nurses that expressed an opposing view as to the provision of adequate information to patients and their families. This has been acknowledged by the patients with cancer, who stated that some nurses provide them with the adequate information when being cared for. A possible interpretation of this contradiction was the different nursing education (and different levels of education) and the specialisation that some of these nurses received as this was discussed in earlier sections. In terms of the allegations made by the nurses in terms of the lack of appropriate policy to regulate the issue of information-giving, it seems that some nurses have taken the initiative to provide the requested information to their patients by drawing upon on their clinical practice and expertise. Overall these nurses were older and more experienced in caring for patients with cancer. In the narratives, even if not verbally stated, it was implied by these informants that they were covert in what they did. These nurses with their demeanour have managed to challenge a long standing perception that physicians should be the only ones to have the authority to inform the patient and his/her family.

Being cared for by clinically competent nurses¹⁰⁹

Naïve Reading

I reached a naïve understanding of the informants' intentions that seemed to consider being cared for by clinically competent nurses as a meaning of quality nursing care. There was a diversity of opinions expressed by the informants when it came to the provision of care in cancer care departments. Some informants felt they were cared for by competent nurses who promoted through their practice a feeling of safety and trust among patients. However, a number of other informants believed they were cared for by less competent nurses, which reflected the perceived level of the provided quality

¹⁰⁹ In Greek-*Na se frontizaun klinika ikanoi nosileftes* -Να σε φροντίζουν κλινικά ικανοί νοσηλευτές

nursing care. There were different meanings that informants attributed to the term “competent nurse”. Therefore it was necessary to request the informants to clarify what they meant when they referred to “competent nurse”. The majority of the informants defined “competent” nurses simply as “nurses who knew what they were doing” whereas a few informants perceived competence as much more than simply professional or technical knowledge. They are nurses who can demonstrate caring behaviours and make you feel safe and able to trust them.

Field Notes: During the narratives patients appeared reluctant to comment on the competency level of their nurses. Unfortunately, the fear rooted in the beliefs of the Greek-Cypriots that if they comment negatively about the care or the health professionals this will result in reprisals, prevented them from articulating their experiences in full. However, patients tend to confide their experiences (especially the bad ones) in casual discussions with members of their family and friends. These experiences are hard to be kept secret especially in a small country such as Cyprus. Again the reasons for this particular behaviour need to be looked for in the ethnohistory of Cyprus and specifically the dominating power that healthcare professionals have had over the patient as a result of their God-like image. To an extent this belief has been preserved over the years. Of course this is an assumption; however certain signs pointed to this direction. Often they tried to avoid answering certain clarification questions which referred to the negative experiences or they tried to change subject or even overemphasising their positive experiences.

Structural Explication¹¹⁰

The structural explication that followed the phase of naive understanding seemed to verify the initial understanding gained from reading the text as a whole. What has been established was the belief that nurses’ clinical competency consists of an essential part of quality nursing care. Through the structural explication the following themes were formulated as part of the main theme:

A. Caring by skilled and knowledgeable nurses.

Informants acknowledged through the narratives the connection between “quality nursing care” and nurses’ competency emphasising on clinical competency. Explicating

¹¹⁰ See appendix C-Table 14

the narratives through thematic explication one realises that the informants valued nurses who were knowledgeable and skilful when performing their duties. Specifically, they referred to the way nurses carried out procedures such as medicine administration, preparation for diagnostic tests, checking the vital signs and starting IV fluids. As a general rule the informants considered a clinically competent nurse, as a nurse that “knows what she is doing”. Further than emphasising the importance of nurses’ clinical competency to quality nursing care informants also stressed the importance of psychological and emotional support as part of the nursing care: *“Nurses felt about me... knew what to do to help me built my confidence level [...]”* (F-21, PI-6, FG-2).

B. Competent nurses address patient’s physical needs through professional knowledge and technical competence.

In this theme I have included the opinions of informants who considered that nurses needed to possess the professional knowledge and skills to address the physical needs of the patient as part of offering “quality nursing care”. Physical needs referred to the daily living activities and varied from patient to patient and included amongst other things, assisting the patient while taking his/her meals, taking the patient to the toilet or shower, giving the patient a bed-bath where he/she was unable to move out the bed and helping the patient to walk. *“Important are not just these technical staff...helping you out of the bed, taking you to the shower, bringing you that extra blanket when you are cold are all of equal importance”* (F-42, PI-16). Informants despite emphasising the fulfilment of patients’ physical needs did not ignore the importance of being skilful in effectively performing specialised nursing procedures. Informants acknowledged the fact that being cared for by knowledgeable and skilled nurses promoted the feeling of safety that patients experienced during their care.

C. Limited availability of cancer specialty nurses.

The final theme was mainly comprised of the advocates’ opinions who also acknowledged the significance of being cared by clinically competent nurses. However, they stressed some barriers of having well-informed and clinically competent nurses caring for patients with cancer. They claimed that the MoH did not provide the

necessary opportunities and resources to nurses to specialise in cancer care. “A common problem in Cyprus is having general nurses treating patients with cancer, most of the times without any additional training or experience” (FG with PA). Cancer nursing training is not provided in Cyprus and nurses wishing to become specialised in this field have to travel abroad and pay expensive tuition fees, which are rarely funded by the MoH. Consequently, patients with cancer are mainly cared for by non-specialised (general) nurses who according to the informants are on some occasions ill-equipped to provide quality nursing care to the patient dealing with several problems caused by his/her illness.

Comprehensive Understanding

The structural explication supported the findings from the naïve reading phase. Patients and their advocates expressed the view that for the provision of quality nursing care, it is necessary that the patients are cared for by clinically competent nurses. Radwin (2000) in a qualitative study of 22 patients with cancer aimed at analysing theoretically their perceptions of the attributes and outcomes of quality nursing care. Eight attributes of quality nursing care emerged from the data. One of these attributes was professional knowledge. As the researcher asserts in the analyses two aspects of professional knowledge were identified: experiential knowledge and technical competence which referred to the importance of skills. Patients and advocates in my study similarly supported the perspective that being cared for by clinically competent and knowledgeable nurses is a constituent of quality nursing care.

The terminology of “competence” revealed the complexity of this issue as it was perceived by the patients and their advocates and raised different interpretations as to the way they understood the term. These variations they attributed to the term reflected the different perceptions of the informants whether they were being cared for by clinically competent nurses. Informants mainly acknowledged clinically competent nurses as, those who held professional knowledge and technical competencies used to deal with the physical needs of the patient, however, some also attributed other qualities to nurses

such as comforting, caring and support used to deal with the emotional needs of the patient. These different interpretations can be attributed to the previous experiences of the patients from being cared for cancer (either in the participating departments either in departments elsewhere) which reflect their expectations. Moreover, the stage of cancer can be considered as a possible interpretation. Patients in a more advanced stage, might value more the emotional support and comfort offered by the nurse. What seem to differ in the different stages of the disease are the needs of the patient which he/she expects the nurse to address. On the contrary, patients in a relatively better state of health might interpret the technical skills of the nurses as the basis for their competency. However, there are no clear boundaries between the expressed opinions from the informants as some patients in the latter group also appreciated the technical skills of the nurses.

A study by Radwin et al. (2005) investigated patients' with cancer descriptions of nurses and nursing care. A total of 461 patients answered the question "In general, how do you feel about the nurse and nursing care". They assert that a typology of four concepts reflecting patients' descriptions of their nursing care emerged from the data. These concepts were laudable, caring, professional and outcomes (p165). The findings of my study support a number of categories included in the first three concepts. The concept of "laudable" included the category "approachable" an aspect of the nurse's qualities that patients with cancer highlighted as been part of the clinically competent nurse by stating that the nurses are "*being there*" (F-21, PI-6, FG-2). Through a trusting relationship patients feel comfortable to open up to their nurses and speak with them "*not only about treatments, diseases but more personally*" (F-42, PI-16, FG-1), an aspect that was identified by Radwin et al. (2005) as "personable". Within the concept of "caring" where data placed in categories labelled supportive, concerned helpful, sensitive, comforting and empathetic (p166). The findings of my study seem to support some of these categories. The informants stressed the importance of the nurse being supportive, understanding, comforting, and helpful. In relation to the category "helpful" a patient said "*She would do anything she can, so my concerns would be heard and even met*". Another patient commented that "*[the competent nurse] is making us feel emotionally comfortable*", whilst a patient referring to the support she experienced by a nurse she

said that “[...] I had to do a dangerous procedure...the nurses were so well-informed and understanding...They felt for me” (F-21, P1-6, FG-2). According to Radwin et al. (2005) the concept labelled “professional” was defined as “holding the standards expected of a nurse in knowledge skills and demeanour and included data placed in categories labelled knowledgeable, responsible, coordinated, dedicated and demeanour” (p166). These findings coincided with the attributes that patients held on what constitutes a clinically competent nurse expressed in my study. Informants expressed the same view as to what a “competent nurse” is; they commented that is the one that “*knew what she was doing*” (F-21, P1-6, FG-2). Informants also supported the view that competent nurses are a prerequisite for delivering quality nursing care, asserting that “[*competent nurses*] are the key to quality nursing care” (FG with PA). Finally, the informants stressed the importance of skills for any competent nurse. Data falling in this category were labelled as “technical competence” a term used by Radwin (2000).

The advocates in the narratives asserted that cancer care is delivered by non-specialised nurses which highlight another aspect which might have caused of some of the inconsistencies in the care when being cared for by specialised and non-specialised nurses. According to them, this in certain situations might cause problems with the care as the nurses are ill-equipped to effectively nurse the patient failing to take into consideration the particularities of the disease. However, at this point the informants appeared to make two assumptions; firstly, that a specialist nurse will ensure competent care and secondly that general nurses are ill-equipped to provide competent cancer care. These assumptions were compared to the relevant literature in order to validate or invalidate them and gain a more insight perspective. The literature is contradictory concerning this aspect of the care. Some researchers appear to suggest that competence and specialty go together whilst other researchers support that specialty can not pledge competency. Parsons (1992) asserts that competence does not mean expert and vice versa. “There are various levels of competence but each of these has a minimum acceptable level or standard” (Hird 1995, p23). What needs to be clarified is the fact the General Nurses are rarely expert, however this does not stop them from being competent. They are competent in performing various nursing procedures methodically.

Although they may appear slow, in time they become more skilful and able to perform tasks simultaneously and faster. Contrary to Parson, a recent study by Aisiku et al. (2007) found that patients appear to be more satisfied with the technical aspects of the care offered by specialised staff in specialised centres rather than the care offered in non-specialised centres. This aspect of the care has also been raised by Viklund et al. (2006) who retrospectively evaluated the care given by specialised nurses to patients with gastrointestinal cancers. The data were collected with two study-specific questionnaires before, during and after treatment. A high percentage of the responders considered the support of the specialist nurse important (87-94%). The researchers assert that this support seemed more appreciated than that of outpatient clinic and surgical ward staff during the diagnostic phase, and during the follow-up it became more important than that of all other team professionals. A second study-specific questionnaire which was given to 49 patients assessed the supportive care. Again, a high percentage (71-94%) of the respondents agreed that the supportive care given by the specialist nurse was satisfactory and important. Viklund et al. (2006, p359) concluded that while some patients had difficulty in understanding physicians' information, none had such problems regarding information given by the specialised nurse. My study supports the hypothesis that the delivery of cancer care by specialist nurses is effective in terms of outcomes and appreciated by the patients. The respondents raised aspects such as "coordination", "support", "provision of information", "comprehensiveness of information" which were also raised by the informants as being important in my study.

Furthermore, informants appeared to agree on the fact that clinically competent nurses promoted a sense of safety and trust among their patients through their practice and attitude. Patients felt being cared for in a safe and trustworthy environment when nurses provided reliable assistance when needed and used their knowledge to honestly inform the patient about treatments, medication and tests. Being emotionally there and being supportive to the patient also contributed to the patients feeling safe when cared for. These findings support the work of Mok and Chiu (2004) who investigated the aspects of nurse-patient relationships in the context of cancer and palliative care. Qualitative data were collected from 10 nurses and 10 terminally ill patients by means of open-

ended unstructured interviews. The patients acknowledged that in those situations whereas the nurse cared for the patient holistically meeting his/her needs in a trustworthy way, “a relationship of trust” evolved. Furthermore, the patients appreciated the fact that the nurse was capable to show awareness of their expressed and unvoiced needs, being available and present, and listened to patients’ deeper feeling and concerns. The findings of my study may also be related with the work of de Raeve (2002) who took a more philosophical approach to the nature of nurse-patient relationship. She explored this nature from the perspective of the patient’s trust in the nurse and what might be said to then render such a relationship trustworthy. She asserts that the patient’s trust in the nurse is initially one of confidence or reliance in the institution and its representatives, rather than in the person of the nurse *per se*. “Patients appear to trust in a nurse’s skills made manifest through her professional qualifications and this must be a partial kind of trust because the nurse may be a complete stranger” (p157). De Raeve (2002) asserts that it is unlikely that a patient would feel he/she has trust in the nurse without spending substantial time with her/him. This way the patient is in the position where “to evaluate whether a nurse is kind or gentle and so on, but not whether she has done the right tasks in ways expected of her”. In these cases where one can not evaluate something for oneself, then he/she trusts some organisation to do this for him/her, then “trust looks more like a kind of confidence” (p157). Trust between people as individuals may emerge and increase, as people become more revealed and known to each other. This is supported by the informants in this study who said that “[...] *after some time...She [nurse] was also a good friend, part of the family...*” (F-65, P1-5). On the same issue de Raeve asserted that there is an intimate connection between caring for and caring about if good nursing is to occur. This argument distinguishes between “caring for” as a task, such as making beds, and “caring about”, where there is an attitude of concern and commitment” (cited by de Raeve (2002, p159). Patients in this study did not made a distinction between the two levels of caring but clearly indicated and appreciated the latter one. A patient commented that the nurses “[...] *felt about me...*” (F-21, P1-6, FG-2) stressing that nurses do not just care for the patient but also care about the patient to talk in terms of de Raeve. However this did not happen instantly as the same patient pointed out “*This did not happen from the beginning of my care...it took time [...]*”. De

Raeve (1996, p21) concluded that “Good nursing in any environment of sustained care requires some degree of *caring about* patients for *caring for* to take place”.

Nurses’ response to patients’ need for care by clinically competent nurses.

Naïve Reading

Nurses held similar perspectives to patients and advocates on the conceptualization of “quality nursing care” as, being cared for by clinically competent nurses, and what constituted competent nursing care. They believed that clinically competent care is not simply the possession of technical competencies and knowledge but these should be accompanied by other qualities such as being caring and supportive. Nurses agreed that through competent nursing care, the patients can experience a sense of safety and trust. Nurses emphasised the lack of specialised nurses in the field and the limited educational opportunities provided to general nurses in relation to cancer care. They supported the views of the patients and their advocates, and felt that any changes to improve this aspect of the care should be focused on the MoH and the hospitals. Finally, they did not seem to share the fears expressed mainly by the advocates that being cared for by non-specialised nurses, can negatively influence the nursing care provided to patients with cancer. However, nurses with limited formal education in cancer care acknowledged that there are limitations to the delivery of psycho-social and spiritual care to the patient and the family.

Structural Explication¹¹¹

The structural explication of the text revealed what has already been acknowledged by the naïve reading; that quality nursing care depends on clinically competent nurses delivering the care. Furthermore, the naïve understanding of the term clinically competent nurse was established by the structural explication. According to this, a clinically competent nurse is considered to be a nurse who concentrates not only

¹¹¹ See appendix C-Table 15

technical abilities and knowledge but also one that has the abilities to care for the patient holistically meeting his/her psycho-social needs, offering the patient emotional support, reassurance and comfort. Through the structural explication, the following themes were formulated as part of the main theme:

A. Clinical competency includes more qualities than technical skills.

It was revealed through the text that the nurses related the provision of quality nursing care with clinically competent nurses. It seems that regardless of the concept “clinically competent nurse” referring predominately to technical/practical skills, the nurses held a more general idea of the concept which included other qualities such as knowing the patient, emotionally supporting him/her, and offering reassurance. “*Getting to know the patients, supporting them emotionally, learning how they behave and how you should react [...]*” (M-31, SNI-6). Unlike technical skills which the nurses became familiar with mainly through their experiences, they acknowledged that for these issues they require the necessary knowledge and training which it is not offered by the MoH or the hospitals. They value these issues greatly and asserted that, in this sense, are requirement of clinically competent nurses as a prerequisite for quality nursing care.

B. Competency promotes the feeling of safety among patients.

The structural explication of the text supported, that caring by clinically competent nurses promoted the feeling that patients were being cared for in a safe environment, which in turn had the potential to promote a trusting relationship between patient and nurse. “*Everything we do and how we do it and how we behave [...] makes them feel safe*” (F-54, WMI-20). The nurse however, needs to develop his/her communication and interpersonal skills in order to gain the patient’s trust. It is through these that the nurse can better know and understand the world of the patient (feelings, worries, desires), be caring, supportive and being there for him/her. If trust is attained then it can, according to the nurses, positively influence the quality of the nursing care. Another interesting aspect of the care that was raised by the nurses was their belief that clinically competent nurses have the capability to care holistically for the patient. They have the ability to

identify the patient's voiced or unvoiced physical, psychological and spiritual needs and accordingly meeting these.

C. Barriers to caring by clinically competent nurses

The nurses identified the fact that there are barriers to becoming a clinically competent nurse as they understand it to be. They considered that the training they received through the nursing school and the programs of continuing education implemented by the hospitals, contributed very little to becoming clinically competent. "Our Ministry and the hospital did not do what was necessary to staff the cancer care departments with specialised nurses who are also trained to address the psycho-social and spiritual needs of the patients" (M-55, WMI-17). Training is focused on the physical care of the patient whilst the other aspects of the care are not given much attention, resulting in being ill-equipped in effectively dealing with the patient's psychological, social and spiritual needs. They also believed that nurses should receive training in the development of their coordination and collaboration abilities, which will facilitate them in providing holistic care to the patients.

Comprehensive Understanding

The nurses in this study gave to the meaning of clinically competent nurse a more general conceptualisation, compare to the one given by patients and advocates, which is not limited simply to the possession of technical skills. They considered that clinically competent nurses should have those abilities to allow them to care for the patient holistically something that at the moment they feel ill-equipped to do, emphasising the existence of barriers to becoming clinically competent. An important barrier derives from the nursing context in Cyprus. According to the directives from the Ministry of Health, nurses working in cancer care departments can be general nurses, as a cost-containment measure. Therefore, they need not to be specialised in the provision of care to patients with cancer nor do they require any additional training in order to gain the necessary knowledge and skills in becoming clinically competent. The ministry claims that the nurses have the skills to become competent and therefore, nurses solely

rely on their experiential knowledge to fill in the gaps in their practice. This fact holds back the nurses from becoming clinically competent. Nurses also believed that through specialisation, nurses can acquire the necessary qualities to effectively and holistically care for the patient. However, as they argue in the narratives the opportunities to specialise are extremely rare and these only begun to emerge recently. The reason for this perhaps lies in the efforts of the Nursing Division to change the fatalistic attitude held by the Ministry of Health in relation to cancer and the care provided to patients with cancer. The findings from the structural explication were discussed in relation to the specific literature, my pre-understandings, the naïve understanding and the context of this study.

Based on my pre-understanding as a general nurse, I asserted that when I referred to clinically competent nurses I did not mean nurses that simply had some technical skills and were technically skilful. This belief derived mainly through my nurse training during which I learnt that a patient is not merely a “number” or a “disease”, but a complete human being requiring his/her needs been met holistically, paying attention to his/her physical, spiritual and psychological dimension. As anticipated, a clinical competent nurse should encompass many other qualities in order to care for the patient. Moreover, the terminology used to describe clinically competent nurses specifically uses the word “clinically” which can easily be misleading. The word “clinically¹¹²” in Cyprus and specifically in nursing is used to describe every nursing practice that takes place with the patient. The word by definition is not limited to those practical skills used by the nurse in order to meet the physical needs of the patient or any other nursing procedure but it also incorporates the psychological, and spiritual care of the patient.

The issue, of patients with cancer being cared for by non-specialist nurses, which was raised by the nurses in my study, has also been discussed in the literature. Two studies have been cited to support the findings of this study. In a qualitative descriptive study by Mohan et al. (2005) the experiences of nurses caring for patients with cancer in non-specialist wards in the west of Sydney were described. Data were collected using a

¹¹² In Greek-*klinika* or *klinikos*-Κλινικά ή Κλινικός

survey and in-depth interviews of nurses. Twenty-five surveys were returned and five nurses volunteered to be interviewed. Mohan et al. (2005) assert that the main themes that derived from the data analyses were: “emotional nature of care, lack of time, lack of knowledge of cancer treatment, family support, environment not conducive to proper care and dealing with patient’s non-acceptance of cancer diagnosis” (p256). The nurses in this study wished to provide quality supportive care for patients and their families but the discouraging environment and inadequate relevant training hindered the nurses’ efforts. In the same light, Sasahara et al. (2003) conducted a survey to investigate the difficulties encountered by nurses who have cared for terminally ill patients with cancer at general hospitals. The respondents identified problems related to communicating with patients and families, their knowledge and skills, treatment and informed consent, personal issues, collaboration as a team including patients and families, environment and system, collaboration among nurses, and near-death issues. The researchers concluded that that nurses working at general hospitals have experienced a high degree of difficulty overall while caring for the patient and acknowledged the need for further nursing education in relation to cancer care.

Tishelman et al. (2004) explored how clinical staff reason about care provision for patients with advanced cancer, through analysis of 20 focus group discussions conducted with staff in three different health care facilities in two Swedish cities. The data analyses emphasised the complexity of care giving for patients with advanced cancer. The researchers highlighted the striking tension between care-giving ideals and limits imposed by the realities of care giving in today’s health system. Informants discussed “the organisation of care, different constellations of relationships between patients, family members and professionals, and theoretical and experiential knowledge as equally important aspects in dealing with all concrete situations in daily practice” (p427). Finally, Tishelman et al. (2004) concluded that nurses in order to provide care for such patients need to have the ability to provide patients with a feeling of safety and trust, having a genuine interest in people, being sensitive, curious, empathic and courageous as well as having a sense of humour (p426).

Meretoja et al. (2002) in a descriptive study identified and classified indicators for competent nursing practice and validated these in a variety of settings. The data were collected from staff nurses, head nurses and nursing directors in an acute 1000-bed university hospital in Finland. The data were analysed to identify generic competencies that were applicable to all clinical working environments. The characteristics of competent nursing practice included 23 indicators with collaboration and coordination, as well as the holistic management of the situation and the needs of the patient being highly recognised (p98-99).

In an interpretive phenomenology study Quinn (2003) looked at nurse's experiences of supporting patients with cancer in their search for meaning. The study included eleven nurses from a medical oncology and a bone marrow transplant unit in central London. The analyses revealed six major themes: the value of experience, understanding the search for meaning, the value of time, the relationships involved, caring and the skills used by nurses, and the difficulties nurses' experienced and the support they needed to continue this role (p166). With the exception of the second theme, the other themes emerged in the narratives with the nurses in my study. A characteristic example was a comment by a female ward manager who commented that "*The patient wants to see a nurse that has a real interest in him/her*" (F-54, WMI-20) which supports the claim made by Quinn (2003) that "central to the nurses" skills was the ability to truly care for the patient" (p169). The emphasis on their experiences as means to cope with difficult situations was stressed by the nurses in this study also emerged in the study by Quinn (2003). According to the researcher, the nurses continually referred to their experiences. They also commented that what "they had learnt was not something that could be taught from books or from college" (Quinn 2003, p166).

Nurses addressing patients' religious and spiritual needs¹¹³

Naïve reading

14

Patients and advocates stressed the need for a holistic delivered care and related the delivery of quality nursing care with the satisfaction of their needs. A fundamental aspect of this holistic approach to care, according to the informants, was the fulfilment of their religious and spiritual needs. Patients prioritised their needs differently, with some patients emphasising their physical needs and others emphasising their religious and spiritual needs indicating at the same time their preference for more individualised care. They viewed the priest as the means by which they could continue their religious life in the hospital through confessing, and receiving the Holy Communion. Some informants seemed to request and receive support from the priest, indicating that they may seek emotional support not only from the nurses and family, but also from the priests. Prayer was an important part of the spiritual norms that the Greek-Cypriots employed when they faced difficult challenges in their lives. For the patients with cancer, prayer was essential because it offered a way to communicate with God. Through prayer people asked for forgiveness and “negotiated” their cure with God. It also served as a stress relief mechanism, through which people expressed their feelings, worries and hopes.

Field notes: During the data collection phase and particularly the narratives I looked for those signs that implied that the patient was a religious person. Based on the Greek-Cypriot religious trends, a person connected with the church/religion would wear a cross around his neck; hold a “knotted rope”¹¹⁴, have the Holy Bible, Holy water, Holy oil or religious icons by his/her bed. Moreover, religious persons tend to make the sign of the cross quite often or say phrases such as “thanks be”, “God help me and the whole world”. As seen in the ethnohistoric review of Cyprus, religion and church are synonymous with the people of Cyprus. The two elements are deeply inherent in the way the Greek-Cypriots live; including the way they deal with health related issues and particularly life threatening illnesses such as cancer and its negative connotations.

¹¹³ In Greek- *Oi nashlestes ikanopoioun tis thriskeftikes kai tis pnevmatikes anagkes tan asthenon*- Οι νοσηλευτές ικανοποιούν τις θρησκευτικές και τις πνευματικές ανάγκες των ασθενών.

¹¹⁴ In Greek - *Komposchini* - Κομποσχοίνι

Structural Explication¹¹⁵

A. Addressing religious needs.

The informants acknowledged that the satisfaction of the patients' religious needs is important to the quality of the nursing care. The patients and advocates referred to several religious rituals which they considered important for their care, however they emphasised on being able to pray in private, confess, study the Holy Bible and other religious books¹¹⁶ and being able to receive the Holy Communion. "*I am sure now that it [religious care] gave me hope and optimism for the future [...] I could not find any better words to describe quality nursing care than what the nurses did for me*" (F-68, P1-25). The narratives showed that patients had at some level their religious needs met both by the nurse and the priest. Reliance on the nurse was focused on taking those actions, to facilitate the religious care being provided by the priest rather than actually providing the care. Such actions included the arrangements for the priest to visit the patient, give the patient privacy to pray, arrangements for the patient to have the religious reading material he/she needs during hospitalisation and where possible take the patient to the hospital's chapel¹¹⁷ for his/her worship.

B. Addressing spiritual needs.

The patients and the advocates did not use the word "spirituality" or "spiritual care" in the narratives indicating perhaps a lack of understanding of the term or amalgamation of the term in the term "religion". However, they elaborated on issues that implied a spirituality unrest which called for spiritual care during hospitalisation. "*The priest helped me to understand the meaning of life [...]*" (M-58, P1-9). The informants seemed to search for existential meanings within the experience of having cancer and with reference to God. Although in this study, spirituality was usually nurtured within the framework of a faith tradition, in the modern world it is possible to see numbers of individuals whose spirituality is either loosely or not at all affiliated with an established religion.

¹¹⁵ See appendix C-Table 16

¹¹⁶ Lives of Saints – In Greek - Βίους Αγίων

¹¹⁷ In Cyprus every hospital has its own small chapel which the patient can visit

C. Barriers to the presence of priest on the ward.

Through the narratives informants highlighted the fact that some nurses and ward managers did not like the idea of a priest being present at the ward performing his religious duties and speaking with the patients. *“I get the feeling sometimes that the nurses do not like the sight of the priest coming to the ward [...]”* (F-21, PI-6). Their aversion was expressed, according to informants, through avoidance and reluctance to make arrangements for him to come to the ward. The patients assumed that the reasons why there was a negative feeling for the priest derived from the belief that his presence was a source of fear and distress for the patients which disturbed the “ward tranquillity”.

D. Holistic care that takes into consideration religious and spiritual needs.

The informants considered the need for holistic care which paid attention to their individual needs, an important aspect of their care and related it with providing quality nursing care to patients. They stressed the otherness of each patient and called for the care to be shaped by his/her individual needs. *“She [nurse] ought to know that we are different with different needs [...]”* (M-21, PI-8). Central to this issue, the informants stressed the need for the nurses to respect and satisfy their spiritual and religious needs.

Comprehensive Understanding

The reflections of my naïve understanding, the results of the structural explication and my pre-understanding in the light of the relevant literature such as the work done by Meraviglia (2002) and Taylor and Mamier (2005) helped me to reach an in-depth understanding of the meaning of quality nursing care as having the patients’ spiritual and religious needs being met. In the literature the terms “spirituality” and “religion” have suffered from a multiplicity of definitions often causing a level of confusion.

Religion is communal, particular and defined by boundaries. It is spirituality incarnated at the social and cultural level. Religion takes the boundless and binds it into the limitations of language and culture, even as it may also transform culture (Pargament 1997). Spirituality was defined by Reed (cited by Taylor and Mamier 2005, p260) as

“the part of being human that seeks meaningfulness through intra-, inter-, and trans-personal connection”. Taylor (2002) also defined spirituality as the “activities and ways of being that brings spiritual quality of life, well-being and function” (p24). Spirituality is about “the inner life or spirit of each of us as it relates to the unseen world of Spirit or of God. It’s the name we give to the dimension of seeing and living that goes far beyond the material world to deeper truths and eternal values (Harpur 1996). It is about “the search for the sacred” (Pargament 1997). Therefore, speaking in terms of Taylor and Mamier (2005) spirituality entails supporting one’s search for meaning, nurturing one’s intra-, inter-, and trans-personal connectedness. Such a view of spiritual care shows according to the researchers that it is not enough for healthcare professionals to support their patients’ religious needs but they should also seek ways to also support them spiritually.

The definitions expressed above coincide with the way the informants viewed spiritual and religious care in this study. What has been revealed by the explication was that informants often used the terms “religious” and “spirituality” interchangeably. Comparing the results of this study with the results of other studies it was shown that some patients expected nurses to support their spiritual and religious needs. Patients with a religious background in this study suggested that their religious needs need to be addressed and most importantly respected by the nurse as part of the care and support provided to the patient to satisfy his/her spiritual quest. The results of my study were similar to those presented by Reed (1992). This was a research study with 100 patients with cancer which attempted to explore the ways that hospital nurses help patients in their spiritual needs. The most frequent responses were interventions not requiring direct nurse involvement: arranging for clergy; allowing time for prayer; providing time for family and helping them to attend chapel. These findings however, suggest that patients perhaps did not have a clear understanding of the meaning of spirituality and spiritual needs. Even though my study was not specifically aiming to investigate, in a deeper sense, the spiritual and religious aspect of care it is shown by the results that patients expected nurses to facilitate these needs. Simultaneously, informants acknowledged the inability of the nurses to satisfy their religious needs, hence not expecting them to do so

but rather supporting these needs through certain arrangements (e.g. arranging for priest). Even so informants made demands in relation to their spiritual needs, expecting the nurses to be involved in the satisfaction of these needs.

Meraviglia (2002) carried out a quantitative study to adapt an instrument to assess prayer activities, experiences, and attitudes of patients with cancer using the prayer scale. A cross-sectional correlation research design was used to study patients with cancer at 3 urban oncology and 2 radiation clinics. Results demonstrated that the patients who used to pray more often than the other patients were those coming from relatively low levels of education and functional status and high presence of metastasis at diagnosis. Prayer however, was identified as a valuable internal resource, which can lessen the effect of cancer. Praying has been identified by Walton and Sullivan (2004) as one of the three main categories of spirituality along with “receiving support” and “coping with cancer”. This grounded theory study included 11 men (ages 54-71), with prostate cancer who were interviewed within several days following radical prostatectomy with bilateral lymph node staging. These studies highlighted the importance patients placed on prayer and of its positive effects on cancer. The findings of my study coincide with these findings stressing that prayer is an important means to the rectification of their spiritual and religious needs. Therefore, nurses are expected to facilitate the need of the patient to pray through providing adequate time and privacy.

My pre-understanding prior to this study in relation to the connectedness of quality nursing care with the spiritual and religious needs of the patient, existed as part of the holistic care that patients need to receive. I was concerned that in the discussions the patients would not be aware of the disparity between spiritual and religious care. However, their references in the narratives suggested that they possessed some knowledge in relation to these issues. Even, if the patients would not use the word “spiritual” I expected them to comment on aspects of the care that would implicitly refer to issues of spirituality. Finally, I did not expect the informants seeking spiritual care from nurses.

The informants identified religious and spiritual needs which while they expected the priest to meet, they also valued the nurses' contribution even though it was significantly less than that of the priests. Informants emphasised the importance of these needs being met by the nurses as part of a holistic approach to care. Their reliance on the priest to meet their spiritual needs again can be interpreted by the role of religion in the lives of the Greek-Cypriots. Father Paisios, a modern saint of the Greek Orthodox Church, when he was talking with one of his spiritual children he asserted that "Being close to God enables us to interpret His acts in the correct way. Therefore, the fact that your child has cancer, should be seen as a blessing for you and your child, through this affliction you can both earn heaven— this is the deeper meaning of life". This illustrates the fact that Greek-Cypriots also trust their priests to facilitate the satisfaction of their spiritual needs (Paisios 2007, p270). This finding however reflected those patients that considered themselves to be closer to the religion and less those that were more relaxed about religion. Therefore, it was shown by the findings that religious patients were more willing to discuss issues in relation to their spirituality with the priest rather than the nurse or any other member of their family. On the contrary, patients more relaxed about religion preferred to discuss such issues with their nurses or some members of their family. However, Taylor and Mamier (2005) assert that there is scanty empirical basis to support this conclusion. Taylor (2003) in a small scale research study with 28 patients and family members living with cancer found mixed results with only a small percentage expecting nurses to provide spiritual care. However, a percentage of patients were enthusiastic about receiving it. On the same topic two older studies concluded that patients with cancer did not consider nurses as primary spiritual care providers. The same studies suggested that patients preferred their spirituality been addressed by family members, chaplains and clergy (Highfield 1992; Soderstrom and Martinson 1987). The relatedness of holistic care to religion and spirituality implied by the informants in my study has been highlighted by Papadopoulos (1999b) who in an exploration of the literature concluded that spirituality is an inherent and important part of holistic care. Furthermore, she asserts that it is now evident the realization that the spiritual dimension must be included in order to achieve the "whole" in holistic care. Govier (2000) asserts that many nurses will probably claim to have a commitment to the concept of holistic

care, in that they will recognise the importance of considering the physical, psychological/emotional, social, cultural and spiritual aspects of need and care. However, the majority of the patients in this study felt that their religious and spiritual needs were overlooked and most of the times delegated to the priest. However, spirituality is according to Papadopoulos (1999b) too critical to be left to the priest, therefore, underlining the significance of the contribution which nurses and other health professionals could and should be making. Neuberger (1998) suggests that health professionals should assume a more active role in the spiritual care of the patient through the lead, training and support that priests can provide them with.

Anderson et al. (1994) assert that holistic care considers the physical, emotional, social, economic, and spiritual needs of the person. Researchers' interest in the connections between mind and body coincides with increasing interest in the holistic view of health care, in which emotional and spiritual needs are considered inextricable from physical and psychological needs (Clark et al. 2003; Damasio 1999). This perspective reinforces the findings from this study that informants desire their needs to be addressed holistically even if they did not use this particular term to express their desire.

Cleary and McNeil (1988) performed a review of the theoretical and empirical work on patient satisfaction with the care delivered. The most consistent finding of this study was that the characteristics of providers (i.e. nurses and physicians) and organisations (i.e. hospital) can result in more "personal" care which is associated with higher levels of satisfaction. "Personal" care for these patients meant that their individual needs were addressed by the nursing and medical staff based on their uniqueness as part of a holistic approach. The findings of my study echoed the findings of Cleary and McNeil (1988) in relation to the satisfaction of the spiritual and religious needs of the patients as a means for providing quality nursing care. It also highlighted the importance that informants placed on respecting their individuality. In the same light the model of quality introduced by Donabedian (1988) stresses the need to address patients' needs, which are represented by the second level of the model named the *Process*. Process is the content of care and measures what happens as care is sought, designed and provided. According

to Kirking and Pharm (1996) the model posits a progression: structural characteristics influence the process of care and hence its quality. Similarly, changes in the process of care influence the effect of that care on the outcome of health status. If this causal link is accepted then the model can serve as an advocator for the findings of my study that needs satisfaction can lead to patient satisfaction with the care delivered.

Nurses response to the patients' needs for religious and spiritual care

Naïve Reading

Nurses responding to the patients' needs for spiritual and religious care believed that these should not constitute part of the nursing care they provide. Justifying their response the majority of the nurses felt that they were unable to meet their patients' spiritual and religious needs due to the fact that their preparation was inadequate; to the extent in many cases this was non-existent. Elaborating on this issue, they revealed that the training they received in the nursing school or the continuing education programs they participated in periodically did not include the spiritual and religious aspect of the patient care. As a result of the absence of nursing competencies in the delivery of such care, a discrepancy existed between their assessment of patients' needs and the individual patients' actual needs.

Field notes: When the nurses responded to the patients' and advocates' views on this issue, I got the feeling from their attitude and non-verbal communication that they underestimated the importance of the patients' religious and spiritual needs. They felt that the patients' physical needs were the most important and assumed that the patients felt the same way.

Structural Explication¹¹⁸

A. Nurses' beliefs on spirituality.

Nurses did not acknowledge the spiritual and religious needs as being part of the nursing care that nurses should offer to patients. *"I do not believe that this aspect of the care [meaning spiritual and religious care] is or should be a part of our job"* (F-50, WMI-

¹¹⁸ See appendix C-Table 17

16). Nurses held the belief that caring for the patient should be focused on his/her physical needs. As a result the spiritual and religious needs of the patients are devalued by the nurses and in most cases left not assessed and unattended. Because of these beliefs, when and where the spiritual and religious needs of the patient are identified by the nurse, meeting them is left to the priests who are considered some kind of “spiritual specialists” who are better prepared and trained to meet these needs according to the nurses’ perspectives.

B. Nurses conceptualisation of spirituality.

Nurses seemed to hold specific interpretations in relation to the meanings of spiritual care. In the narratives the nurses used the term “spirituality” instead of the term “religious” therefore it seemed that the two terms were synonyms and are used interchangeably. “*Spiritual Care...? If you are referring to issues related to the religion [...]*” (M-39, WMI-11). When asked to clarify the meanings that they attributed to the term, they reported religious rather than spiritual aspects of the care. This belief serves as an explanation as to why they relied on the priest to deliver this kind of care, and why they felt that this care should not be provided by them. The interventions identified by the nurses were in proportion to their understanding of the term “spirituality”. They believed that their responsibility for spiritual and religious caring should only be limited to arrangements that will facilitate the satisfaction of these needs, by inviting for example the priest or any other spiritual person to talk to the patient, instead of them providing the spiritual care.

C. Restraints for spiritual and religious care.

A number of barriers were identified which impeded the spiritual and religious caring of the patient. A major barrier was the domination of the bio-medical model in clinical practice. “*We are lucky if we can meet the ‘more’ important needs [meaning physical] of the patients*” (F-25, SNI-2). Since nurses applied the principles of this model in practise they mainly focused on assessing and addressing the patient’s physical needs and not his/her spiritual and religious needs. Those nurses that received some kind of additional training for caring for patients with cancer were aware of these needs and included them

in the nursing care plan. However, the nursing interventions were often not structural and depended on the nurse. Another barrier that was identified was the lack of adequate education on spiritual and religious issues. This was probably the reason why nurses held the belief that spirituality refers only to religion and religious issues. It may have also served as a justification for not considering the satisfaction of these needs being part of the nursing care and therefore not assuming this role but instead referring the patient to the priest. Finally, nurses claimed that due to their heavy workload and poorly staffing levels in the cancer care departments, there was not enough time to address these needs.

Comprehensive Understanding

The majority of the nurses expressed the view that spiritual care is not and should not be part of their job, an attitude which threatens holistic caring. This belief is not something uncommon in the literature (Sawatzky and Pesut 2005; Kuuppelomaki 2001; Greenstreet 1999). However, a small number of nurses believed that the patient needs to be cared for holistically and that this care includes the satisfaction of the patient's spiritual and religious needs. The idea of holistic care has been established in the literature and researchers such as McSherry (2000) and O'Brien (1998) assert that the claim that nurses should take account of aspects of spirituality derives from a holistic perspective on human functioning.

Narayanasamy (2007) asserts that spirituality forms part of a holistic perspective, meaning that a human being consists of body, mind and spirit and that these dimensions are interconnected and interdependent. Therefore, these researchers and many more consider spirituality, as an integral part of the nursing domain (Van Leeuwen et al. 2006; Taylor 2002b). The rejection of the belief held by many Greek-Cypriot nurses also came from international nursing associations such as the ICN. The ICN Code of Ethics states: "In providing care the nurse promotes an environment in which the human rights, values, customs and spiritual beliefs of the individual, family, and community are respected" (ICN 2000, p2). Yet for various reasons, most nurses often miss opportunities to provide the spiritual component of holistic care. However, generalisations should

again be avoided as there were examples of nurses actually supporting the spiritual and religious needs of their patients.

In my study I came to the conclusion that the nurses that were religious and shared the religious persuasion of their patient were more able to acknowledge the importance of this aspect of the care and act upon it. *“Yes I would say that I am a religious person, I mean I believe in God, go to church every Sunday, fast when I have to, and take the Holy Communion. I understand the patients that are religious wanting to continue their duties while in hospital [...]”* (F-50, WMI-13). Another nurse asserted that *“Caring for the patient’s spiritual and religious needs is a necessary as part of the holistic caring, I admit that I have many duties and many patients to care for during my shift, but whenever I can or whenever the patient needs to have these needs met I will do my best to support him/her”* (F-31, SNI-7). Therefore, these nurses in their clinical practice supported their patients in their religious duties. They took the initiative to call the priest to visit some of the patients on the ward and even took the patients to attend the church at the hospital’s chapel. These nurses also appeared comfortable to discuss with the patients issues around cancer and death and of course about the real meaning of life.

Nurses are overwhelmed from doing so many physical things for the patients during the shifts that rarely any time or energy is left to address other needs including spiritual needs. These findings coincide with a recent qualitative study by Van Leeuwen et al. (2006) who aimed to gain insight into the spiritual aspects of nursing care. The sample was made up of the specialist fields of oncology, cardiology and neurology and divided into groups of patients, nurses and hospital chaplains. The study identified several barriers and facilitators reported both by patients and nurses in addressing the spiritual dimension of the person in the care. Explicitly, “patients saw that nurses were busy and understood that they had little time and attention for a conversation” (Van Leeuwen et al. (2006, p882). Similarly the nurses acknowledged that time is an issue that potentially influences the provision of spiritual care to the patients. Nurses claimed that it is a matter of having to set the right priorities implying that spiritual care is perhaps not been considered as a priority of the care. Van Leeuwen et al. (2006, p882) assert that “time”

was used by the nurses as an avoidance mechanism and this was expressed simply as a lack of time, however what they really meant was that they did not feel like talking. The dominance of medical–technical aspects that cause tensions between cure and care was also identified as a potential barrier to the provision of spiritual care, an aspect which has also been highlighted in my study. Explicitly, nurses asserted that this model mainly focuses on the physical and technical aspect of the care resulting in the other aspects of the care not being given adequate attention.

Those nurses and ward managers that recognised that spiritual care was part of a holistic approach to nursing care, claimed that their nurse training has offered them very little to prepare them for this challenge. They believed that changes need to be introduced in the nursing curricula so that emphasis is given to holistic care which includes spirituality. For those nurses that work in cancer care departments this kind of education needs to be continuous and consistent. Lemmer (2002) in a survey with 130 randomly selected baccalaureate nursing programs explored how the spiritual dimension of nursing care currently is being taught. The findings indicate that these programs recognised the spiritual dimension of care as a component that should be included in preparing students for their professional roles. This is evident in the widely reported inclusion of the spiritual dimension in program philosophies and in curricula across all program types. In addition, program attitudes reflect agreement that holistic nursing care includes the spiritual dimension and that spiritual care can be taught. Viewing care recipients holistically provides according to Lemmer (2002) an avenue for teaching nurses and student nurses to assess and meet patients' spiritual needs. Similarly, "recognition of spirituality as a component of culture offers guidelines for addressing spirituality within a framework that respects diversity of beliefs and values" (Lemmer 2002, p487). However, this implies a potential risk, which can be summarised in limiting one's understanding of spirituality and in failing to recognise a broader view of components of spirituality. These components may include one's search for answers to questions about the meaning and purpose of life, one's search for forgiveness, giving and receiving love and maintaining relationships and connectedness with self, others and a higher power (Reed 1992; Emblen 1992).

Despite that the research literature highlights the existence of other components of spirituality as perceived by the patient and nurses, my study emphasised the fact that the informants viewed spirituality mainly as been connected to religious issues. Based on McSherry et al. (2004) classification of the different meanings of the concept of spirituality, the Greek-Cypriots appear at one extreme to support a strictly religious meaning and at the other extreme a strictly humanistic, existential meaning. This multidimensional approach is not only a result of philosophical analysis, but can also be concluded from empirical evidence (Johnston Taylor 2005; Flanely et al. 2002). Flanely et al. (cited by Van Leeuwen et al. 2006, p876) "implicitly emphasised that the multidimensional approach of spirituality, by holding that a strictly religious interpretation of spirituality is problematic for an adequate assessment of the spiritual needs of, particularly, non-religious patients". Perhaps the manifestation of spirituality through religion can be explained by the ethnohistoric background of the Greek-Cypriots which revealed that religion and religious issues occupy a significant space in their lives. However, it was shown by this study that some of the nurses were not particularly religious (did not practice religion regularly) and as a result they found it difficult to assess and address the spiritual dimension of their patients' needs. However, according to the informants' narratives the problem seemed to be more obvious when they had to care for patients that were strict religious persons who ascribed a religious dimension to spirituality and failed (intentionally or not) to understand spirituality outside the beliefs of the Greek-Orthodox faith. The endistancement of not religious nurses from religion and church prevents them from understanding the connection between religion and spirituality. As a result they asserted that it can sometimes be difficult and burdensome not being able to grasp the meaning of spirituality and the ways that the patient's spiritual needs can be addressed. The findings however, do not imply that only religious nurses can provide this kind of care. The fact that some nurses and patients were not particularly connected to religion comes as a verification of a changing culture in Cyprus where more and more people are not adhering to religion to the same extent.

The strong influence of these cultural elements supports the findings by Baldacchino (2006) who argued that, although the spiritual dimension might be concealed, patients' spiritual needs should be given attention, which should be manifested through nursing care behaviours. This may be influenced by culture, which is according to Walker et al. (1995, p49) "a potent force in shaping beliefs, moderating behaviours and giving meaning to experiences".

In the literature it is evident that it is the nurse's responsibility to assess and address these important needs of the patients during hospitalisation. One of the primary aims of the nurses needs to be the continuation of the patient's spiritual and religious life while in the hospital. However, an issue that arose from the explication was whether the nurses in Cyprus received, during their basic training enough information and acquired relevant skills which would allow them to effectively assess and address the patients' spiritual needs. These claims made by the nurses were not supported by other empirical studies in Cyprus. In the international literature Piles (1990) stressed the need for spiritual care content in basic nursing programs. According to Pile the "level of practice of spiritual care is positively related to the degree of educational exposure in the nurse's basic program" (Piles 1990, p38). This study revealed that 96.5% of the nurses sampled (n=176) believed that holistic care included spiritual care, but that 65.9% felt inadequately prepared to perform spiritual care skills. A descriptive exploratory study by Baldacchino (2006) investigated nurses' competencies in the delivery of spiritual care to patients with myocardial infarction. Data were collected by means of an open-ended questionnaire on qualified nurses (n=77) followed by an in-depth interview on a stratified random sample (n=17) of nurses from the same respondents. The study demonstrated the complexity of spiritual care, and the researcher emphasised that the nurses are required "to increase their awareness of the uniqueness of each individual patient with regard to the connection between mind, body and spirit; the assessment of the spiritual status of patients during disease and the implementation of holistic care as recommended by the Nursing Code of Ethics" (p894). In an earlier qualitative study by Schnorr (1988) involving 46 nurses recognised by health care providers and care recipients as providing spiritual nursing care. She found that most of the nurses reported

minimal preparation as best from undergraduate nursing programs (Schnorr 1988, p133). Similarly, Narayanasamy (1993) in a study of British nurses found that the nurses sampled believed patients had spiritual needs, but the majority (66.6%) believed patients' spiritual needs were either poorly met or not met at all. The need for more education in relation to spiritual issues was recognised by the majority of the nurses (>60%). In a study involving 208 nurses a significant number of which were oncology nurses, Sellers and Haag (1998) reported that the primary sources of nurses' knowledge about spirituality and spiritual interventions were clinical experiences and continuing education. Not surprisingly, only 15% of the nurses participated reported that basic nursing education was the primary source of learning about this aspect of nursing care (Sellers and Haag 1998, p338).

Being cared for in a nursing environment which promotes shared decision-making¹¹⁹

Naïve reading

The patients and their advocates referred to the meaning of quality of care as an ability to participate and in some way manage their own care. They stressed their inability to participate in decisions relating to their health care. However, they asserted that the nurses similarly did not give them the opportunity to participate in those specific aspects of the care that were a nursing duty. The nurses not only gave the patient no options concerning his/her nursing care but at the same time they seem to condemn the knowledge and appraisal of their patients instead of respecting and integrating them in their care.

The Greek-Cypriot culture is very specific when it comes to making decisions. Therefore, it encourages individuals to express the reasons for supporting or rejecting something. In the same way for the health care issues patients expected the health care

¹¹⁹ In Greek – *Parochi frantidas mesa se ena nosiyleutiko perivallon pou na praagei tin apo kainau lipsi apofaseon* – Παροχή φροντίδας μέσα σε ένα νοσηλευτικό περιβάλλον που να προάγει την από κοινού λήψη αποφάσεων

professionals including nurses to do the same (e.g. rejecting a treatment option, doing the bath at 8am in the morning instead of the afternoon). However, sometimes there appears to be a tension between this belief and their reverence for authority. As discussed earlier in this chapter, gender related issues as well as the image that the public holds for their professional carers contributed to a reverence for the authority which they find difficult to challenge.

Patients claimed that their inability to participate in such decisions was based on the provision of insufficient information from the medical and nursing staff, the staff's attitude and finally the nature of the hospital policy that did not promote SDM (shared decision-making). Patients' advocates recognised this problem and offered a possible solution. They asserted that taking an active role in the process of SDM requires the law, government policy and the governing bodies of the nursing and medical profession to move from paternalism in the direction of informed choice. Participation needs to be introduced and established both by brave legal decisions and attitude change.

Structural Explication¹²⁰

The patients and their advocates reported SDM as an important aspect of their own health care which they consider an indicator of the quality of nursing care. Through the structural explication the following themes were formulated as part of the main theme:

A. Barriers to patient involvement in shared decision-making.

Informants identified the ability to participate in their own care as an integral constituent of the quality of nursing care. They believe that they have the right to participate in the SDM process and opportunities should be given to them both by the physicians and the nurses to do so. There is growing consensus that patients ought to be more involved in their own care. "[...] is all about choices to be made in collaboration with your professional carers" (M-44, PI-18). This agreement stems from political ideas, ethical thinking, and research in health care. With the introduction of the NHIS in Cyprus, the patient's position is moving towards being a customer; evidence is an increasing degree

¹²⁰ See appendix C-Table 18

of personal choice and personal rights, care guarantee, and a right to self-determination (Polyneikis 2006). However, patients acknowledged that although they desired to actively participate in aspects of their care they were deprived this opportunity. “*No I was not given the opportunity to participate in decision-making even though I wanted to*” (F-58, PI-23). The reasons I identified in the narratives are assumptions made by the patients, based on their interactions with physicians and nurses and mainly based on the response they received when they expressed the wish to decide for themselves for specific issues concerning their care. They believe that this aspect negatively influenced their care and specifically the way they viewed the quality of the nursing care they received. “*[Not participating in decision-making] is for me a negative aspect not only for the nursing care but for my health care in general*” (M-44, PI-18). Patients when they are admitted for treatment often feel solely dependant on other people. Professional carers make all the decisions about them for them; this is a cruel feeling that often makes people feeling useless and powerless. The narratives highlighted that the issue of power and empowerment seem to be related to the provision of appropriate information to the patient so that he/she can acquired the knowledge and he/she can understood the options he/she has to choose from. Due to the absence of a healthy information exchange, which perhaps raises issues of bad communication between formal health care professionals and their patients, the patients’ valuable knowledge and appraisals are left unexploited. Instead, sometimes health care professionals including nurses demonstrated condescending behaviours towards the patients and their families, something that the patients felt disappointed with and commented negatively about.

B. Nurses’ and physicians’ hegemonic attitudes.

Informants assert that nurses’ and the physicians’ attitudes are the main barriers when it comes to their ability to participate in their own care decisions. “*[...] the mentality of the staff [physicians and nurses] is so hard-headed [...]*” (F-58, PI-20). Informants suggest that nurses and physicians have the belief that they should determine the care and treatments that the patient needs and that, they should have complete control of the situation. “*Is a deeper thing, is about the impression that the physician and the nurse*

know best [...]' (M-42, PI-10). Informants also indicated that perhaps health care professionals want to avoid having their power challenged by patients. Participation is linked to power and empowerment. Power is seen by health care professionals as extrapersonal, indicating that an increase in one's power must be balanced with a decrease in someone else's power. This stereotype thinking of healthcare professionals also extends to the way they deal with the patient. They do not have faith in the patients being capable to take an active role in health related decisions. However, health care professionals including nurses may be overlooking an important fact; that in Cyprus the patients are becoming more and more educated, informed and vigorously participating in associations protecting and promoting their right to participate in the decisions about their care.

Field Notes: During the narratives I had the chance to spend plenty of time with the patients and the health care professionals. I observed that nurses and physicians tend to behave differently towards younger rather than older patients. Younger patients seem to be receiving more information in comparison to older patients, and are given more opportunities to ask for clarifications in relation to their treatments, tests and care. There are two possible interpretations to this fact. Firstly, the younger patients possibly asked more questions of the health care professionals and express more vigorously an interest to be involved in decision-making. Alternatively, health care professionals estimated the preference for SDM presumably on the basis of the patients' age assuming that older patient often lack decision-making capacity.

C. Lack of policy to promote SDM.

Patients' advocates being more aware of policy and legal issues concerning the care, they focused their responses in highlighting the lack of relevant policy to introduce and promote SDM in clinical practice. *"[...] there is not a policy that regulates the involvement of patients in the decision-making process [...] patients' influence in these decisions is usually minimal to none"* (FG with PA). As a result they believe that health care professionals and especially nurses and physicians often "hide" behind this lack of involvement and, do nothing to empower the patients to take a more active role in their health. However, it should not be concluded that they may not be familiar with SDM and what this process entails. As a result nurses seemed to overlook an important aspect of

SDM; that it can promote patients' outcomes and improve patients' adherence and prudence.

D. Cultural issues

An issue which patients and their advocates identified in the narratives and which was seen as a barrier to the promotion of SDM in clinical practice, derived from the cultural background of the Greek-Cypriots. Informants referred to the beliefs and values that people hold in relation to health professionals and especially physicians and nurses. "*The icon of the health care professionals as Gods*" (FG with PA). As was already discussed in the chapter 4, health professionals are perceived by the people as being something like "Gods", and the professionals themselves have an attitude which somewhat matches patients' beliefs. Based on these beliefs it is therefore acceptable for health professionals to assume the control of the patients' treatment and care, without him/her being an active informant in the whole process and without his/her desires really been raised or being addressed. Nowadays however, the people of Cyprus are gaining more education and becoming more aware of many aspects concerning their health, which is slowly contributing to the people challenging this cultural attitude.

Comprehensive Understanding

In order to reach to a comprehensive understanding of the narratives, I have reflected on the naïve understanding, the structural explication, and my pre-understandings as well as the context of the study, the research questions and the literature such as the work of Cox et al. (2006), Sainio and Lauri (2003) and Tattersall and Ellis (1998). According to the literature, patient participation in decision-making has produced many debates among health care professionals. "Shared decision-making, in which patients and health professionals join in both the process of decision-making and ownership of the decision made", is attracting according to Coulter et al. (1999, p318) considerable interest as a means by which patients' preferences can be incorporated into clinical decisions. Sowden et al. (2001) assert that the SDM model is not only desired by patients and is

also being advocated as a way of promoting clinical effectiveness and more appropriate use of resources.

According to my pre-understanding, I did not expect the majority of patients to wish to participate in SDM processes, or even sharing the responsibility of their choices with their health care professionals. This pre-understanding was formulated having in mind the collective nature of the Greek-Cypriot society, which becomes more noticeable especially for older patients, since it is usual that in these cases, for decisions to be taken collectively by the family instead of the patient himself/herself. My pre-understanding was not formulated once and for all in relation this collectivist nature of the Greek-Cypriot society. The fact that culture is dynamic and can constantly change and adapt oneself to the changing circumstances was kept in mind. However, the observation of the patients and their families that participated in this study reinforced my initial pre-understanding of how these families functioned in relation to decision-making. Furthermore, the desire for more information in relation to health issues should not be associated with a desire for participation. I did not expect patients wanting to assume the control for their decisions. There are two main reasons for this. Firstly, I believe that due to the confidence that people attributed to their professional carers over time, they trust that the decisions they make will be in their best interest. Moreover, people are reluctant to challenge professional carers on their decisions, fearing that a possible conflict might lead to reprisals, even if this is just an assumption and a fear that only exists in the patients' mind. Secondly, people feel that they do not have the expertise, knowledge and confidence to assume the responsibility for their decisions and prefer professional carers to decide on their behalf.

My pre-understanding thoughts were also raised in the literature. Cox et al. (2006) assert that even though nurses and other healthcare professionals need to sufficiently inform their patient in order to promote their participation in decision-making, it should not be assumed that this is the patients' preference. As this aspect of the care was highlighted by the results of my study, the need for constant assessment of the patients' willingness to participate in decision-making processes emerged as an issue. This is also supported

by Cox et al. (2006, p264) who also assert that the patient's preference for the degree of involvement in decision-making can be affected by various factors such as age and gender. These two factors are well documented in the literature (Salkeld et al. 2004; Pinquart and Duberstein 2004; Iconomou et al. 2002; Jenkins et al. 2001). According to these studies it appears that older patients with cancer prefer to receive less information about their illness and treatment preferring this way a more passive role. This is partly explained by the age-associated cognitive decline (Pinquart and Duberstein 2004, p69).

In my study, as I have emphasised earlier in my field notes, healthcare professionals including nurses appeared to have a different attitude in relation to the provision of information and participation in decision-making processes between the relatively young (aged 21-30) and the older patients (aged 42-58). This was reflected in the narratives where the lack of opportunities to participate in decision-making was raised by the relatively older patients. For the younger patients this issue did not seem to concern them and instead they focused in other attributes of quality nursing care such as "being with their family". A male patient, aged 21, asserted "*The staff (referring to physicians and nurses) is very cooperative in this department, they kept me informed from the first minute of my admission...they explain everything to me and my family [...]*". On the same issue a female patient, aged 30, asserted that "*Sometimes it is difficult to decide by myself, I feel safer if they...if we make the decisions together (meaning with healthcare professionals)...but I am happy with the way they try to get me involved*". As far as the oldest patients (aged 59-68) that participated in this study, it was shown from the narratives and the focus groups that their majority did not express the desire to participate in the decisions in relation to their health. This finding comes as a confirmation of the ethnohistoric background of the Greek-Cypriots and its influence on the people of Cyprus. These patients are aware that their family will take care of them as they have probably done in the past and therefore, they do have to worry for issues pertaining to their health. The patient knows that any information can be given to his/her family and when decisions need to be taken then the patient can rely on his/her family to take the best possible decisions on his/her behalf.

In relation to the effect of gender on patients' preference to receive information and participate in decision-making processes, the literature is contradicting. Whilst other studies show that men are more willing to take an active role in their care, other studies show otherwise (Hagerty et al. 2005; Jenkins et al. 2001). According to Butow et al. (cited by Cox et al. 2006) the change in status of disease can also consist of a factor that influences participation in decision-making. Moreover, Beaver et al. (1999, p266) carried out an exploratory study to examine decision-making role preferences and information needs for a sample of people with colorectal cancer. The work replicated a larger study carried out for women with breast cancer (n=150). The study concluded that the majority of patients with colorectal cancer (78%) preferred a passive role compared to 52% of breast patients with cancer. The results of my study do not seem to verify the findings, suggesting that change in status of disease can affect the patient's participation in decision-making. However, the results that suggest that the gender of the patient can influence patient participation in decision-making seem to be verified. In the specific context of Cyprus, it seems that the gender can negatively influence the patient's participation in decision-making. Explicitly the women that participated in this study appeared more reluctant to participate in decisions that pertained to their health in comparison to the male patients. The reason perhaps lies in the status of the women in Cyprus, which I have already discussed in chapter 4. Most physicians and an increasing number of nurses in Cyprus are men and therefore, women find it difficult to challenge the decisions taken by men especially women of the third age.

The patients and their advocates expressed the belief that nursing care and specifically its quality is influenced by the ability patients have to participate in their own health care decisions. They believe that this can be achieved through the provision of opportunities to participate and the provision of choices, and empowerment¹²¹. In the narratives the informants did not use the word "empowerment" but instead they used synonyms of the word "power", indicating perhaps their unfamiliarity with the term. However, in Greek the two words have similar meaning. The word "power" which can be translated in

¹²¹ Empowerment – in Greek- *ενδυνάμωση*.

Greek as “δύναμη” (*denami*) or “ισχύς” (*iches*) mean to have power; therefore having synonym meaning to the word empowerment.

The fact that the patients expected the nurses (and physicians) to give them the power to participating in SDM processes coincides with the literature which supports that a patient must be an active informant in his/her empowerment, indicating that nurses can facilitate and support patient's empowerment (Laverack 2005). The active role that the patient should be engaged too, has been stressed by Kuokkanen and Leino-Kilpi (2000) who assert that empowerment is an individual process in which the person is interacting with the environment pursuing impact on his/her life. The responsibility to invite patients to actively participate in decision-making in nursing lies with the nurse. This is so according to Kuokkanen and Leino-Kilpi (2000) because the patient is in a subordinate position and can not be expected to take the lead. Patients' experiences in relation to health issues should be valued as evidence contributing to the decision-making process and, that partnership with health care professionals is important (Rycroft-Malone et al. 2004a). Contrary to this prerequisite of SDM, informants in my study repeatedly stressed that their experiences and knowledge in relation to health issues have not been valued by the nurses, nor have been used to promote participation; instead patients were often treaded with contempt. *“I told her that for me this medication is not effective and asked her the reason for giving me a different one [...] I was disappointed because she ignored me”* (F-58, P1-23). The idea of God like power of the physicians which extends to include the nurses might serve as an explanation to some of the behaviours demonstrated by the nurses. In clinical practice nurses often use the physician's instructions to strengthen their position in their relationship with the patients. *“She said to me “because this one is better for you and the physician prescribed this one”* (F-58, P1-23). However, it may also be the case that nurses behave in such a way in order to conceal their own lack of knowledge or avoid engendering conflict with the patient. Therefore it appears that a prerequisite for decision-making is the relationships between patients and health care professionals. Particularly, it appears that the issue is the balance of power and control. Instead of having a paternalistic approach to the patient and professional carer relationships, it is more facilitating to

SDM if the relationship is open and equal so that patients have the opportunity to express desires, concerns, information needs and willingness and opportunities to participate in their care (Sainio et al. 2001). Further, there is a need for a context receptive to change, addressing power and authority processes, and with appropriate and transparent decision-making processes (Rycroft-Malone et al. 2004b).

Since the patients and their advocates raised the issue of participation in the decisions concerning their health care, I felt that there should be a clarification of what exact interpretations the patients and their advocates attributed to the term. The informants identified key characteristics of SDM which confirmed the research findings from other studies that preceded this one (Lemonidou et al. 2003; Coulter 2002; Charles et al. 1999). The concept of SDM, as understood by patients' and advocates', was experienced as being informed, being able to have choices and maintaining a sense of control. Moreover, the informants asserted that at least two informants -carer and patient- be involved in the SDM, that both parties share information, that both parties take steps to build a consensus about the preferred treatment or care, and that an agreement is reached on the treatment/care to implement.

Patients with cancer related the inability to participate in the decision-making process with poor information giving, lack of relevant policy and the staff's attitude. Moreover, the fact that patients feel that the lack of appropriate and sufficient information, is the main reason for making them powerless in the decision-making process, has been reported by Sainio and Lauri (2003). They performed a study in order to identify, to what extent patients with cancer participate in decision-making and, to what extent background characteristics, information obtained and relationships with staff, explain the extent of patients' participation in decision-making. Data were collected with a structured questionnaire and qualitative interviews. With regard to decision-making about nursing care, patients wanted to participate in decisions about activities of daily living rather than those about technical issues such as choice of treatment (p254). They concluded that it is necessary to make it easier for patients to participate in decision-making; this can be achieved by informing patients more about such opportunities and

by encouraging them to participate. Sainio and Lauri (2003) assert that the better informed the respondents were, the more they took part in decision-making (p258). These findings appear to support the findings of my study which suggest that patients with cancer want to participate in decision-making and acknowledge the provision of information as an important vehicle to achieve this. The response by a male patient, 44, who said that *“If I had more information I would be able to be involved in the decision – making process”* summarises their willingness to participate and the need for more information to enable them to do so. Tattersall and Ellis (1998) also stressed the importance of providing adequate information as a basic prerequisite of patient involvement. Informants of a cross sectional survey of 250 Scottish patients with cancer by Meredith et al. (cited by Tattersall and Ellis 1998) highlighted the need for information about their chances of cure and about side effects of treatment as a high priority. The close link between the provision of information and the ability of the patient to participate in SDM highlighted by Tattersall and Ellis (1998) has also been stressed by both the patients and their advocates in my study.

The question of what information is appropriate and adequate for the patients in my study; depended first and foremost on patients’ own perceptions. Therefore patients’ information priorities varied. However, as a general principle patients required detailed explanations about the condition and its likely outcomes with different treatment alternatives, medicine indications and side-effects, test results, diagnostic tests to be taken. These findings correspond with the relevant literature that patient’s preferences determine what kind of information should be provided (Coulter et al. 1999; Entwistle et al. 1998).

Nurses’ response to being cared for in a nursing environment which promotes shared decision-making

Naïve Reading

Nurses were invited to respond to the views expressed, by the patients and their advocates, in relation to the development of a nursing environment that would promote

SDM as an aspect of the concept of quality nursing care. A naïve understanding was formulated of the nurses' response to this main theme as follows:

Nurses acknowledged that patient participation in the nursing care through SDM is a part of its quality and agreed with the patients who suggested the existence of such connection. However, nurses acknowledged that the patients were not given opportunities to participate in SDM processes in relation to their nursing (or medical) care. Nurses identified attitude, training, time constraints and policy issues as the barriers for empowering patients through the promotion of SDM in clinical practice. Finally, the nurses commented on those cases where the patients for various reasons did not wish to be involved in SDM, or to assume responsibility for decisions concerning their health.

Field Notes: During the narratives I noticed a disappointing mood on behalf of the nurses when expressing their perspectives on this issue. Although I avoided making any specific comments on my observations, soon I realised that the nurses felt as if they were trapped in an unpleasant situation. They wanted to empower the patients by involving them in the care but felt powerless to do so. Presumably they felt this way because of their limited power to influence clinical practice and their limited training and skills to include patients in decisions.

Structural Explication¹²²

Through the narratives the nurses expressed their belief that “quality nursing care” relates to the empowerment of patients through increased participation and specifically SDM. The majority of the nurses supported the findings from the patients and advocates narratives with provisos, highlighting the importance and need for patients to take a more active role in their own health care. However, the nurses identified barriers and facilitators for achieving increased participation of patients in terms of the nursing care delivered to them.

A. Involving patients in SDM based on patient's preferences.

What has been acknowledged by this study, is whether the nurses have made accurate estimations on the patients' real preferences on assuming or not, a more active role in

¹²² See appendix C-Table 19

their care. “*What happens if the patient does not want to participate in such decisions? [...]*” (M-27, SNI-3). The narratives show that nurses in practice, tended to overestimate the willingness of their younger patients to participate in SDM strategies and concurrently underestimated their older (chronological) patients desire to participate in such strategies. It seems that their assumptions were based on their cultural values. As was discussed earlier the collective nature of the Greek-Cypriot society, according to which decisions for elderly patients are taken collectively; that is, the family, decides on the care and treatment options for their parents. Therefore, in such cases the patient is not given the chance to assume active role in his/her care, instead a member of the family assumes this role on his/her behalf. In more traditional families this “rule” may also apply to young adults. Other factors that seemed to influence the desire for an active involvement in the care were the gender and the educational background of the patients. Nurses claimed that male, young and more educated patients were more likely to want to participate, rather than women and patients with lower or no education. In any case, it is the responsibility of the nurse not to assume what the preferences of the patient are, but to actually identify these through effective communication. An active role in care should not be compulsory for the patient; it should be based on his/her preferences, which the nurse is bounded to respect.

B. Nurses attitudes towards SDM

Barriers and facilitators for the implementation of SDM in practice have been reported by the nurses, these were clustered under the category “nurses attitude”. Many nurses probably think they already are doing a good job of educating patients and involving them in decision-making, despite some growing evidence to the contrary. “*Physicians and nurses hold a certain view that they “know” what is best for the patient and want to have complete control*” (F-22, SNI-1). A few nurses seem to prefer a more paternalistic role which they are used to and genuinely feel that such an approach is better for their patients. The motivation of the nurses to put SDM in practice was identified as a facilitator whilst the potential threat that SDM will have on the nurses’ professional autonomy was perceived as a barrier to its implementation. Further, to this perceived risk, the belief that the nurses and other professionals know everything about the patients

and are trained and experienced to take the best decision for the patient is also impeding the implementation of SDM.

C. Barriers to implementing SDM

Nurses claimed through the narratives, that for the introduction of the SDM in nursing clinical practise, it is important to make adjustments to the health care system (i.e. nursing services division) and the specific laws¹²³ pertaining to the nursing practice. As a related barrier to SDM was the perceived lack of organisational support through adequate training for the development of the necessary skills. *“It is difficult to involve the patients [...] not enough time or the support or the policy to engage them in this process”* (F-35, SNI-9). The nurses feel that the SDM implies a movement of responsibility towards the patients, unlike the present situation, where the full responsibility is with the nurse. As a result of this change, nurses fear that there will be an increased risk of legal actions¹²⁴. Even though nurses seemed willing to increase patients’ involvement, expressing positive attitudes towards SDM they stressed the need for training, so that the relevant skills can be developed. They also acknowledged that in practice this might mean that more time should be spent with the patient before reaching a mutually accepted decision. Taking into consideration the workload that nurses are expected to meet, in combination with the poor staffing levels, this can act as a barrier to the successful implementation of SDM in practice.

Comprehensive Understanding

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body”

Benjamin N. Cardozo (1870-1938)

I have included this quote by Cardozo in order to demonstrate and stress the importance of the patients’ fundamental right to participate in decisions pertaining their treatment and care. Nurses agreed that the patients should be given the option and the

¹²³ Cyprus Nursing and Midwifery Laws Number 214/1988 – Number 30(1) 2006.

¹²⁴ Perceived increase in malpractice liability.

opportunities to assume an active role in their care by making their desired choices. This consecutively, is perceived as integral part of quality nursing care provided to the patient. However, researchers such as Joffe et al. (2003) assert that confidence and trust in carers and treatment/care with respect and dignity are more closely associated with patients' overall evaluations of their care than adequate involvement in decisions. The active involvement of patients in their care, often referred to as participation and autonomy¹²⁵, is evidently related to the experience of increased satisfaction from the nursing care received. A growing body of literature coincides with these connections made by the nurses, the patients and their advocates (Suhonen et al. 2007; Sahlsten et al. 2007; Florin et al. 2006).

In order to gain a more in-depth understanding the findings were related to appropriate literature. As with the patients and advocates where concept clarifications of what SDM meant for them was acquired, the same clarifications were retrieved from the nurses. The nurses provided a view of SDM based on the collaboration between the patient and the nurse. Their descriptions can be related to the definition provided by Briss et al. (2004) who consider SDM as a decision-making process jointly shared by patients and their health care providers and which aim according to Howie et al. (2004) at helping patients play an active role in decisions concerning their health, which is the ultimate goal of patient-centred care.

The majority of the nurses expressed the opinion that their patients are generally deprived of opportunities to participate in SDM. However, there were a few nurses that expressed an opposing view in this issue. They asserted in the narratives that regardless of the lack of policy and the time constraints they are up against in the clinical setting they have given their patients some choices in relation to the nursing care provided. A female nurse, aged 50, asserted that "*Involving the patient in decisions related to his/her health is not easy in the clinical setting, not with having the physicians opposing such a development [...], but the patients do not ask much of us, most of them simply want to be*

¹²⁵ The fundamental right of a person to make choices for his/her health care is often referred to as autonomy.

informed...who would like to be in the dark anyway...I know I would not want that". What these nurses identified as the real barrier to be involving patients in decision-making processes is their own beliefs. *"Let's be honest...what we affraid the most is overcoming our own beliefs...things have changed and there is no going back...it costs us nothing to ask the patient what he/she prefers and provide the appropriate care based on his/her preferences, breaking the routine is not the end of the world it is just the beginning of a new one"* a female nurse, aged 45, asserted. On the same topic a male nurse, aged 35, emphasised that *"It is time to start caring for the patients based on his/her own preferences and at the same time getting them to be more involved, I have been doing it in my practice and to be honest it feels great just to see the patient be satisfied with apparently small things [...]"*. Reflecting back to the ethnohistory of Cyprus and the narratives of the patients and the nurses, one realises that what the above nurses managed to do and which separated them from the majority was to rise above their hegemonic attitudes. They adopted a more patient-centre approach to care and abandoned the paternalistic approach that is nourished by the healthcare context in Cyprus.

These nurses believe that their constant contact with the patients creates a positive relationship based on trust that allows them to act as informative agents. This nurse-patient relationship makes the patient, in some cases, to expect the nurses to offer them the relevant information and opinions on what they should or should not do, or even let the nurses decide on their behalf. Nurses seem to share the views expressed by the patients and their advocates that, the main obstacles for the lack of SDM are the staff's mentality and the MoH policy which nourishes a rather paternalist approach to clinical practice. Presently in Cyprus, there is not a relevant policy towards the introduction and regulation of SDM in the public or private sector. This policy gap "allows" healthcare professionals, including nurses, to decide for the patient without the patient participating. They believe that changes need to be introduced in the policy, so that SDM can be implemented in clinical practice with the launch of the NHIS. O'Connor et al. (2004) stressed the importance of related policy which should address the issue of SDM in clinical practice. This fact together with certain characteristics of the Greek-

Cypriot nurse, which were discussed earlier, stressed for the adoption of such policy as to achieve the successful involvement of the patients in their care. Nurses in Cyprus are increasingly faced with situations in practice regarding the prolongation of life and withdrawal of treatment of patients with cancer and, in light of these developments; they need the relevant policy and resources to be able to meet this challenge. On the same topic, Breier-Mackie (2001), asserts that although nurses play a central role in the care of dying people, they may still find themselves disempowered by medical paternalism or ill-equipped in the decision-making process in end-of-life situations.

In the Greek-Cypriot context, the nurses expressed the view that time was one major constraint to implement SDM in clinical practice. They believe that due to the excessive workload that they are expected to fulfil and the poor staffing levels, it is difficult to utilize the necessary time for enabling and engaging the patient to assume an active role. Similarly, in the literature, time constraint was also cited as a barrier for SDM. Time proved to be a major concern for health professionals across many different cultural and organisational contexts (Schulman-Green et al. 2006; McGuire et al. 2005; Ford et al. 2003). However, Gravel et al. (2006) assert that recent evidence about the time required to engage in a SDM process in practice is conflicting, indicating that the engagement can be accelerated with the appropriate training of health care professionals and the provision of effective decisions aids for patients (p21).

Another barrier to SDM which was stressed by the nurses in my study was the need for organisational support through nurses' training. The importance of SDM competencies has been stressed by Elwyn et al. (1999) who assert that it is almost impossible for patients to participate in SDM, if nurses and physicians do not have the skills required to involve patients in decisions. Lack of self-efficacy was mentioned by a growing body of literature (Suurmond and Seeleman 2006; Naik et al. 2005; Bajramovic et al. 2004) as a perceived barrier to the implementation of SDM. This suggests that strategies to implement SDM in clinical practice will need "to include training activities targeting health professionals" which according to Elwyn et al. (cited by Gravel et al. 2006, p26) it was possible. However, Gravel et al. (2006) assert that future implementation studies

in this field will need to focus on improving knowledge of how competencies in SDM can be sustained over time.

Through the narratives the nurses expressed the view that the patients' real preferences were not acquired in relation to their willingness to participate or not in SDM. Moreover, it was revealed that many nurses were preoccupied as to the profile of the patients that were willing and not willing to assume an active role in their care; a preoccupation that was probably driven by their cultural background. These findings support the findings of Florin et al. (2006) who concluded that registered nurses are not always aware of their patients' preferences and as a result tend to overestimate patients' willingness to assume an active role. They assert that nurses do not "successfully involve patients in clinical decision-making in nursing care according to their own perceptions, and not even to the patients' more moderate preferences of participation" (p1498). A thorough assessment of the individual's preferences for participation in decision-making seems to be the most appropriate approach to ascertain patient's involvement to a preferred level of participation. The categorisation of patients as preferring a passive role, collaborative role or active role is seen as valuable information for registered nurses to tailor nursing care. The assessment of the individual's preferences for participation in decision-making however needs to be on an ongoing basis as the willingness of the person to participate may vary at different times. Therefore, issues such as how well the person feels, their understanding of the prognosis as well as the stage of the illness are some of the issues that can potentially alter the patient's preferences. Similar findings came from Millard et al. (2006) who introduced the notion of an "involving-non-involving continuum" which was used to evaluate the behaviour of informants, based on their preferences to participate or not in their nursing care. This continuum was based on five typologies of behaviour according to which patients were categorised: "completely involving"; "partially involving"; "forced involving"; "covert non-involving" and "overt non-involving". Therefore, according to Eldh et al. (2006), in order to provide conditions for true patient participation, professionals need to recognise that the patients carry with them valuable and unique knowledge which the healthcare professional needs to respect and considered rather than

just inviting the person to participate in decision-making. My study's findings in relation to the desire of some patient not to be involved in their care are supported by Robinson and Thomson (2001) who assert, that while there is an increasing emphasis on patient empowerment and SDM, evidence suggest that many patients do not want to participate in decisions about their own care. It is important for the nurses to remember that autonomy is a choice, not a command. Patients and families must be able to look to their health carers for expert advice and guidance as they confront the myriad of decisions involved with their treatment and care. Deber (cited by Robinson and Thomson 2001, p36) discussed the obvious discrepancy between the strong belief in the importance of patient autonomy and the existing literature that appears to suggest that many patients may not wish to be active informants in making treatment decisions. The need to better understand patient preferences for participating in clinical decisions is highlighted. Robinson and Thomson (2001) assert that a number of empirical studies have suggested that, even if patients wish to be informed about their condition and options for treatment, they might not wish to be actively involved in making the treatment decision.

Patients being with and involving the family in the nursing care¹²⁶

Naïve Reading

The text was read several times to grasp its meaning as a whole and to formulate a naïve understanding of the text. Being with and involving the family in the care is perceived by the informants as a meaning of quality nursing care. Through the narratives the patients and the advocates acknowledged the importance of the family to the patient valuing its' contribution mainly on the physical and emotional aspect of the care. Just the "closeness" of family was reported in many cases as a reassuring and supporting means, and made the patient feel being cared for in a familiar and safe environment.

¹²⁶ In Greek – *I ikogenia vriskete konta kai anamigniete stin nosileftiki frontida ton asthenon* – Η οικογένεια βρίσκεται κοντά και αναμειγνύεται στην νοσηλευτική φροντίδα των ασθενών.

Field notes: Family plays an important role for the Greek-Cypriots especially when a serious illness such as cancer has occurred. For someone not having a Greek-Cypriot cultural background it would be beneficial to report here some of my observations. Family members spend significant time with their patients where the visitation policy allows it. In many cases they are involved in the care by addressing the patient's every day activities. Family bonds appear so strong that some relatives requested to be present at the narratives, expressing this way their constant concern for their loved one and protecting him/her against any harm that the interview might cause.

Structural Explication¹²⁷

A. Being with the patient and emotionally supporting him/her.

A patient receiving quality nursing care means being with his/her family and receiving emotional support by them. *"To me quality nursing care is having my family with me during these difficult times in my life"* (F-58, PI-11). Informants acknowledged the importance of family presence when being cared for, especially when receiving care in the hospital. The family presence is recognised by the informants as a supportive mechanism used to deal with the experience of being cared for and having cancer. The family can offer the patient courage (*tharos*) and hope (*elpida*) to deal with the experience of having cancer and its consequences.

B. Family supporting patient's physical and informational needs.

The informants recognised that the family involvement in the care was materialised though addressing some of the patient's physical, informational and decision-making needs. *"I see the role of the family as complementary to that of the nurse for giving us quality nursing care"* (F-44, PI-13). Explicitly this care was focused on providing the patient help with some of his/her everyday living needs, an aspect of the care for which many of them had already assumed responsibility at home. Informants reported that the family can work together with the nurses to help the patient with his/her physical needs such as taking their medication, walking about and getting dressed. The role of the family for providing information and supporting the patient's decision-making during the care, was also highlighted by the informants. Finally, they identified the need that

¹²⁷ See appendix C-Table 20

nurses should be working towards encouraging the family in assuming a more active role in the patient's care.

Comprehensive Understanding

Since this is hermeneutic phenomenological study, I considered it important to clarify what the informants referred to when they used the term "family". According to Mcilpatrick et al. (2006, p295) assert that the term family has usually been defined as an individual of blood relationship, even though a broader definition would seem more appropriate and is best defined "as those individuals considered as family by the patient". Therefore, the term family for this study included those individuals of blood relationship, friends, and significant others that the patients considered as family.

The structural explication came as verification to the naïve understanding of quality nursing care being understood by the informants as being with and involving the family in the patient's nursing care. These findings coincide with the belief that patients' illness experiences can not be understood as individualised, socially isolated phenomena (Mcilpatrick et al. 2006; Mystakidou et al. 2004). Rather, Thomas et al. (cited by Mcilpatrick et al. 2006, p295) that "a serious illness such as cancer carries with it considerable psychological and social consequences for the family, carers and other close associates of the people with the disease". As cancer also affects the family rather than just the patient, the family may choose to assume a more active role in their loved ones care; that is in the hospital or at home. However, in some closed societies such as the one in Cyprus, family's involvement in the care is not a matter of choice but it is rather imposed on them as a silent cultural rule. Nurses' being the product of their society also share this belief held by their patients and expect them to need their families nearby when being cared for. Despite evidence that these supportive relationships can increase adherence to treatment and improve medical outcomes Sayers et al. (2006) assert that the impact of close relationships are likely dependent on the degree to which the patient perceives a need for family involvement.

My pre-understanding in relation to the role that family plays for the patient with cancer was formulated by my cultural background. As has already been discussed in chapter 4, the Greek-Cypriot society has many collectivistic characteristics which can be traced in the value they attributed to the family institution. Family remains a powerful institution in Cyprus; with its influence extending into every aspect of the people's lives, including health issues. Therefore, I anticipated that the informants would raise this issue as an aspect of quality nursing care. I expected collectivist elements such as the SDM among the family members and the patient, the presence of the family with the patient, and their active participation in the care to be at the forefront of the informants' views.

Speice et al. (2000) in a qualitative study with 19 focus groups (11 patient and 8 provider) from 8 cancer centres in the United States concluded that family members are an integral part of a patient's cancer care, from the moment the diagnosis is delivered to the conclusion of treatment. The researchers assert that there should be an agreement between healthcare professionals, patients and their families as to the best way to involve the family in the care (p101). Similarly, Mystakidou et al. (2004) assert that the health care team-patient relationship is a triangle not a dyad, consisting of the health care professionals, the patient and the family. They stressed that "each part supports the relationship between the other two, and each is affected by what else happens in the triangle. Ongoing open communication between patients with cancer and family members is essential, both between each other and with healthcare professionals" (p9-10). Healthcare professionals need to support patients and family members in expressing their emotions by "letting family members know that emotional stress and behavioural changes are not uncommon during illness, that these and other problems can be overcome with patience and support" (Mystakidou et al. 2004, p11).

The results of my study highlighted that the patients and advocates recognised the contribution of their family in making decisions related to their care. Family members were often the link between the patient and the nurse when information was provided to the patient. Their mediation assured that the information would be in a language understood by the patient and based on this, the necessary decisions could be made.

These findings correspond to the findings of Sekimoto et al. (2004), who performed an interview survey at an outpatient clinic in Kyoto with 134 informants to test the hypothesis that Japanese patients would wish to participate in treatment decision-making if adequate information were provided, and the decision to be made was clearly identified. The results showed that patients have positive attitudes towards participation in decision-making when this is supported by adequate information giving. The study highlighted the important role of the family in decision-making. Some patients involved their families in decision-making, indicating their desire to receive support from their families, in order to support their decision-making. Even though this study showed that many patients wished to involve their families in decision making, “very few would allow their family the final decision” (p5).

The informants, through the narratives, expressed the belief that the closeness with their family and its involvement in the care, had benefits which primarily took the form of physical and emotional support (coping mechanism). Bean et al. (1980) in a qualitative study interviewed 33 outpatients receiving chemotherapy at the Temple University Hospital’s oncology clinic in the USA. They concluded that the family is an important coping mechanism for patients suffering from cancer. However, they also acknowledged that the support patients receive from their family is not always without problems, emphasising the fact that it is unrealistic to expect the patient with cancer to deal effectively with the disease, when those around him/her are denying its existence. Recently Pandey et al. (2003) in a pilot study investigated the views of 15 patients with oral cancer in Trivandrum (India) in relation to their concerns and their coping strategies. Support by the family and significant others were perceived by the patients participating in this study, as the second most common coping mechanism. Coping refers to the thoughts and acts used by the individual to manage the internal or external demands, or both, that tax or exceed his/her psychological resources. The coping is conceived as a dynamic process dependent on the person environment transaction and needs of informal carers. Thomas et al. (cited by Mcilpatrick et al. 2006, p296) conducted a 3-year multi-method study in the UK on the psychosocial needs of patients with cancer and their main carers. The study obtained its data from 644 returned postal

questionnaires (carers n=262; patients n=382), 79 in-depth interviews with patients (n=47) and carers (n=32) and 39 structured interviews with a variety of health personnel involved in care services. The results indicated that carers were engaged in both care work tasks and demanding emotion work. The latter was a crucial aspect of what informal carers did, which included managing the emotions of the patient, as well as their own. This revolved according to Thomas et al. (cited by Mcilpatrick et al. 2006, p296) around “being there” for the patient; “being positive”, maintaining hope and trying to maximise the sense of “life carrying on as normal”.

Nurses’ response to patients’ need being with and involving the family in the nursing care

Naïve Reading

The naïve reading of the narratives concurs with the perspectives expressed by the patients and advocates. Nurses seem to agree on the important role that family plays for the patient and its realisation as a meaning of quality nursing care. Nurses considered the support of the patient by his/her family members as beneficial not only for the patient but also for the health care team and the family members. In terms of the potential positive influence on the patient, he/she better adheres to the suggested treatments and care, the patient has his/her family close, and finally nurses claimed that it was more likely that these patients would have better health outcomes than those whose families were not close to the patient or involved in their care. For the health care professionals including nurses it is beneficial that the patient is more cooperative and adherent to care. Furthermore, family members are involved in the care by actually providing physical care and at the same time developing the bonds with their patient and get to spend more time with him/her.

Structural Explication¹²⁸

The structural explication of the narratives was performed in order to examine the text and explain what it said. Parts of the text that have a meaning of their own were identified and excerpted from the text. The meaning units were compared with each other, arranged and sorted according to meaningful connections. The content of the meaning units was condensed, abstracted and organised into sub-themes, themes and main themes. The nurse's response to the need of the patient of being with his/her family and involving the family in the care materialised in two themes and 8 sub-themes.

A. Nurses beliefs on family presence and involvement.

Nurses acknowledged the importance of the family for the patient and believed that through their presence and involvement in the care, quality nursing care can be achieved. "[...] providing quality nursing care it to involve the family in the care" (M-31, SNI-6). "Family and friends contribute to a better nursing" (F-51, WM1-18). It seemed that the nurses shared the value that patients' placed on the family's contribution to the care and moreover, think that this care compliments the care delivered by the nurses. "[...] they fill in the gaps of our care" (F-51, WM1-18). The family's presence was considered by the nurses to be a form of involvement in the patient's care since it appeared to have a positive influence on the patient with cancer. "[...] giving them the chance to be with their patient is involvement" (F-51, WM1-18). Finally through the narratives, nurses expressed their belief that those patients receiving support from their families and friends appeared to have better health outcomes and better collaboration with the nurses. "Patients tend to have better health outcomes, getting better sooner [...] and be more collaborative with us" (M-31, SNI-6)

B. Need for family presence and involvement.

Nurses acknowledging the benefits that family presence and support have for the patient and therefore they encouraged through their practice the family's involvement in the

¹²⁸ See appendix C-Table 21

care. *"We need them to be there instead", "I encourage them to spend more time with the patient, sometimes even outside visiting hours [...]"* (F-45, WM-14). Family members were urged to spend more time with the patient; however this was in accord with the patient's preferences. Some patients expressed the desire for not having their family around, at least not constantly or outside the designated visiting hours. *"Sometimes the patient does not want to have them around [...] they also want some peace of mind"* (F-45, WM-14). The text of the nurses' responses revealed that the family can facilitate the communication between nurse-patient and the decision-making. *"[...] not having the knowledge to understand the medical or nursing vocabulary or having a reduced comprehensive level rely on their relatives to be informed and take serious health decisions"* (M-41, WM-15). Finally, nurses' narratives highlighted the importance of family presence which allows the nurses to train the family in order to be able to assume the caregiver's role, for when the patient will return home and assure the continuity of the care. *"It is his/her family that will assume the caregiver role, and for this to happen they need training"* (M-41, WM-15).

Comprehensive Understanding

One understanding of the meaning of quality nursing care, as disclosed through nurses' narratives, is that quality nursing care is closely related to the presence and involvement of the family in the care of the patient. My results add to the growing body of literature that indicates that nurses and other healthcare providers, patients' families, and patients have positive attitudes toward family presence. The connection between family presence and involvement with quality nursing care has not been entrenched by the literature although these findings come as a confirmation that incorporating family presence supports both patients and their families (Timmermans 1997). The findings from the structural explication were discussed in relation to the naïve understanding, the context of this study, specific literature and my pre-understandings on this topic.

Reflecting on my pre-understanding on the issue of family presence and involvement, I realised that these derive from my cultural and nursing background. As a Greek-Cypriot

I was taught about the importance of the family in every aspect of the people's lives including health. Family relationships can grow stronger when one of its members is faced with difficult situations such as when diagnosed with cancer. Families are expected to work together to get through such difficult situations. I as a nurse, but also my colleagues have adopted this belief in clinical practice trying to take advantage of the potential positive outcomes from involving family in the care; working therefore towards a more family-centred approach to care. However, one should not ignore the adverse consequences that the involvement of the family may entail. Drawing upon my experience and the lived experiences of the nurses in this study there are times that the presence of family members can be a nuisance and hold up the smooth running of the ward. However, these incidents are isolated and the important role that the family can play in the care of the patient can not be diminished by these.

Azoulay and Pochard (2003) assert that in intensive care units the patient is usually unconscious and/or incompetent so that the relationship shifts to the family. Interactions between nurses- and other caregivers- and families usually follow one of three models. In the first model, "a member of the family receives information from the professional caregivers but does not participate in decisions or physical care" (p545). In the second model, the members of the family assume a more active role by communicating the the patient's wishes and values to the professional carers. In the third model, the family members assume even more active participation in the care by actually providing physical care to the patient and participating in decision-making. The researchers assert that there is a need for the adoption of a family-centred care model and for better communication between the patient-family-caregiver (p548). The nurses', patients' and advocates' text discloses that in the Greek-Cypriot context of the cancer care departments, the interactions between nurses and families usually follow a combination of the second and third model described above. This indicates the strong influence of the family in the care of the patient that calls for a family-centred approach to care in combination with a more liberal visitation policy.

The findings from the nurses' text showed that the nurses and the other informants, being interviewed in my study, seemed to have a positive attitude towards the family presence and its involvement in the care, favouring its application to practice. These findings coincide with the findings from a survey by Duran et al. (2007) who described and compared the beliefs about and attitudes toward family presence, of clinicians, patients' families, and patients. Surveys were completed by 202 clinicians, 72 family members, and 62 patients. Even though, clinicians had positive attitudes toward family presence, they expressed concerns about safety, the emotional responses of the family members, and performance anxiety (p276). Duran et al. (2007) highlighted that "nurses had more favourable attitudes toward family presence than physicians did" (p275). Patients and their families had positive attitudes toward family presence (p277). Many of the family members and patients in this study had prior experience with family presence, a situation that might have influenced their positive attitude toward family presence. This is an important finding which was not directly highlighted by the informants in my study. However, based on my experience from working in several public and private hospitals in Cyprus, family presence and involvement is a widespread phenomenon, even if not always being endorsed by everyone. In another study, Meyers et al. (2000) were the first to use the family presence protocol developed by the ENA (Emergency Nurses Association) to study the experiences of nurses and other healthcare providers and patients' families (p32). In that study, 96 healthcare providers and 39 family members who were involved in an episode of family presence, reported positive attitudes toward family presence. Nurses expressed a more positive attitude than did either attending or resident physicians, and believed that family presence helped meet the emotional and spiritual needs of a patient's family; empowered the family members; helped the family understand the patient's condition; gave the healthcare providers an opportunity to educate the family, allowed the family to help both the patient and the staff; and caused the providers to be more considerate of the patient's dignity, privacy, and need for pain management. These findings correspond to the findings of my study, where nurses also commented on the empowering role that the family plays for the patient. Family members often assumed a communication liaison role between nurse and patient and supported the patient in making decision in relation to their health. These

findings are also supported by Ohlen et al. (2006) who performed a qualitative study in Canada to explore how significant others were involved in patients' decisions. In total, 61 patients with early and advanced-stage breast and prostate cancer and 31 significant others participated in semi-structured interviews. Using constant comparative analysis, "four main types of decisional involvement by significant others were identified: creating a safe place for the patient to make a decision, "becoming a team": collaborative decision-making, moving the patient towards a decision, and making the decision for the patient" (p1625). However, a hermeneutical study by Lindholm et al. (2007) which investigated the perspectives of thirty-seven significant others about the care on the basis of open, structured questions came to contrasting results. The researchers concluded that significant others have not had any place or domain in the nursing care provided for their loved one. Lindholm et al. (2007) assert that the role of the significant others can take three different forms "participation in the outer room of care as an observer, present in the inner room of care as a participant, or ignored in the no-man's-land of care." (p176). No matter what their place is, the significant others feel that through caring conversations and information gained in an ethical manner can come to share the suffering that characterises a breast cancer patient's situation. Therefore, the researchers stressed that it is the nurse's responsibility to encourage patients and their significant others "to create a sense of communion as regards the battle against illness, in which suffering is addressed" (p179-180).

In my study some nurses expressed a contradictory belief, claiming that some patients did not favour family presence and involvement. *"It should not be taken for granted that all patients want their family members around all the time [...] it is not uncommon to have patients that simply want to be alone and when their relatives are with them they get irritated and restlessness [...] in these situation it is my duty to intervene and kindly request from the visitors to leave"* a female ward manager, aged 54, said. This finding has at least three interpretations. First, some patients might not have a good relationship with some of their family members and therefore, not favouring their presence in the hospital. Alternatively, due to personal or family characteristics some patients may become more emotional or more distressed when family members become involved in

their care, due to their inability to handle the situation. Finally, some patients who are in relatively better health may not feel that the family's involvement and presence is necessary-an interpretation also supported by Sayers et al. (2006). According to Sayers et al. (2006) nurses and other health care professionals should pay attention to the patient's preferences before inviting the family to get involved in the care or be present with the patient. "Patients who are in relatively better health may not feel that involvement is necessary or welcome" (p317). Lewis and Rook (cited by Sayers et al. (2006, p318) assert that "attempts to influence the patients' health-related behaviours have been shown in samples of older patients, to engender greater psychological distress".

Epilogue

I do not agree with the word “conclusion” particularly in this kind of research, because it suggests a finality and surety about the exploration and interpretation of the phenomenon under investigation. However, in hermeneutic phenomenology one can never claim that the interpretation is complete or that the data have been saturated or that he/she has reached the “absolute” truth. The word conclusion would not do justice to the hermeneutic nature of this study. Instead I preferred to use the word epilogue. In Greek the word *epilogos*¹²⁹ stands for peroration of a speech. This word despite giving a closure to the chapter it also allows for further investigation by the reader or the researcher himself/herself.

Patients, their advocates and the nurses provided their perspectives on the meanings of “quality nursing care”. It seems that quality nursing care is desired by patients and promised by nurses. The findings coincide with the findings of earlier studies that a simple definition of “quality nursing care” does not exist highlighting its complexity and ambiguity. Patient, nurses and advocates seem to agree with the most of the attributes of quality of nursing care raised in this study. One way that nurses and patients described “quality nursing care” was in terms of the qualities that the nurse needs to have, signifying that the nurse is an imperative part of quality nursing care. Surprisingly, patients appeared to be more able to define what is not quality of nursing care, rather than what it is. Advocates focused more on the policies and legal aspects of the care.

In terms of the individual narratives and the narratives of the patient group there were differing elements which were observed during the analysis of the data. Whilst in the individual narratives the patients raised concerns pertaining to their individual issues and problems they faced when being cared for, in the focus groups narratives the informants were more concerned about patients in general even if personal experiences were used by the informants to support their claims. Due to the fact that the informants that were included in the focus groups were the same as the ones that were individually

¹²⁹ Etymology comes from *epi*- EPI meaning “upon, in addition” + *logos* meaning “word”

interviewed, very little new information emerged in relation to the attributes of quality nursing care. The reason for this was that the focus groups were performed in order to achieve breadth rather than depth of the data that were retrieved from the individual interviews. Therefore the informants were asked to comment on the attributes of quality nursing care that emerged from the individual narratives and state whether they agreed or disagreed with these. As it was expected the focus groups were more politicised, with the informants criticising the Health Ministry's policy for patients with cancer and the provided cancer services. They provided personal examples (experiences) in order to demonstrate some of the problems they had when being cared for. They also used positive examples of how care should be in the clinical settings, acknowledging this way that not everything is wrong with their care or the healthcare professionals that deliver this care. Another observation made in the focus groups, is the fact that the informants appeared united as one voice when it was requested of them to comment on their nursing care. They apparently saw the focus groups and the research as a whole as a unique opportunity to raise their voices and map their problems in order to get better cares in the future.

We often try to be professional, focusing on the main picture and trying to analyse everything on the basis of scientific explanations and interpretations; however it was seen from my study that it is often the little and simple things that count to and appreciated by the patient. It is seemingly simple acts, such as being there, holding a patient's hand and listening that bring such profound changes in comfort when one is ill. Moving on to the next chapter what was found by this study to be important to the patient was translated into guidelines of good practice.

PART 4

CHAPTER 7

Produced theory and its practical application through guidelines for nursing practice

Introduction

In this chapter, the implications of the work that has gone before are related to the development of descriptive theory, explaining, based on the theoretical framework of hermeneutic phenomenology and quality, the findings of this study. A practical application of the theory is also provided through the development of guidelines for nursing practice. The rationale of why aim at a practical level of the findings lies in the fact that nursing is a practice profession, whose clinical focus, provides the ultimate justification for research and scholarly work (Ferguson-Pare et al. 2002; Hoffart and Woods 1996). Furthermore, Gadamer asserts that hermeneutic understanding includes a unit of understanding, interpretation and application. Application is a “fundamental element of all understanding, for without application one can not speak of understanding” (Lindholm et al 2007, p174).

In principle, the concept of quality nursing care might relate to practice in a number of different ways. It might for instance provide a perspective from which to evaluate the likely impact of policy changes; suggest new directions for practice development; provide an organising framework for education; or prompt new research questions. Against the background of the Cyprus nursing context and the current developments in cancer care I chose to illustrate the professional relevance of the concept by proposing a series of guidelines for practice, which I believe will likely be beneficial for nursing and the patients with cancer under these circumstances. A brief discussion of the nature of guidelines is presented. This is followed by a description of the method by which the guidelines were developed. Finally, the developed guidelines are introduced in order to illustrate the general approach proposed by this study.

Producing theory through philosophy

In the literature there are various definitions of what theory consists of, a fact that reveals the complexity of the concept. Meleis (1997, p12) defined theory as “a symbolic depiction of aspects of reality that are discovered or invented for describing, explaining, predicting, or prescribing responses, events, situations, conditions, or relationships”. Theory has been described by Streubert-Speziale and Carpenter (2006, p11) as “a systematic explanation of an event, in which constructs and concepts are identified and relationships are proposed and predictions made”. Chinn and Kramer (2004, p268) defined theory as a “creative and rigorous structuring of ideas that study a tentative, purposeful and systematic view of phenomena”.

Two types of theory, descriptive (factor-isolating) and prescriptive (factor-relating) have utility for nursing (Meleis 2006; Chinn and Kramer 2004). Prescriptive theories include “propositions that call for change and predict the consequences of a certain strategy of nursing intervention” (Meleis 2006, p44). Meleis (2006) defined descriptive theories as theories that “describe a phenomenon, an event, a situation, or a relationship; identify its properties and its components; and identify some of the circumstances under which it occurs” (p44). Since this type of theory has the potential to describe a phenomenon, describe its effects as well as hypothesize why it occurs therefore, explanatory, relating and predicting utilities can be attributed to descriptive theory. The latter characteristic, adds a predicting component to descriptive theory, therefore by using this type of theory one can predict when a phenomenon may occur as well as the circumstances under which this phenomenon is not likely to occur. This is of particular importance to this study and explicitly the phenomenon of quality nursing care, and the circumstances under which it can occur or not. In the narratives the informants have identified these circumstances as well as those measures that need to be taken so that these circumstances can be achieved in clinical practice, therefore achieving quality nursing care. Knowledge resulting from phenomenological enquiry becomes according to Van der Zalm and Bergum (2000, p213) “practically relevant in its possibilities of changing the manner in which a professional communicates with and acts towards another

individual in the very next situation he/she may encounter". Therefore, the importance of the produced theory extends beyond the Cypriot nursing context to also include the international nursing context. The reasons for such claims vary but the two most important are described here. The phenomenon of quality nursing care has been interpreted using a different theoretical, conceptual and methodological approach and at the same time the perspectives of patients, advocates and nurses were retrieved in relation to this phenomenon offering a more holistic perspective. As a result, this study's outcomes challenge the existing interpretations on the term quality nursing care as well as the circumstances under which this phenomenon occurs. The generation of new knowledge in relation to phenomena, as in this study, appropriates the development of descriptive theory according to McKenna (1997).

Hermeneutic phenomenology served as the methodological and philosophical basis for this study and Ihde (1971) claims that its aim is the understanding of a phenomenon through recognition of its meaning. There was an initial scepticism on the possibility of producing theory through the use of hermeneutic phenomenology or simply hermeneutics due to the differing notions regarding the nature of knowledge obtained from this approach (Hesook and Ingrid 2005). This study however, avoided these errors made by the precedent studies on the same topic. Therefore, the nature of the produced knowledge and theory were clearly defined as well as their usefulness in practice was clearly explained. Moreover, two important elements of hermeneutic phenomenology which are considered as the frames within which knowledge of people's everyday experiences and practices (i.e. lived experiences) is gained through interpretation, that of context and history were taken into consideration in the collection, analysis and interpretation of the data. Therefore, the consideration of these elements and their integration in this study coincided with the development of descriptive theory in precise terms through hermeneutic phenomenology.

Hesook and Ingrid (2005, p153) assert that the theory development from the phenomenological perspective requires "a definition of descriptive theory that is appropriate in the tradition" and the one proposed by Meleis has been identified as such

by Van der Zalm and Bergum (2000) who assert that “the descriptive and interpretive elements of the written textual forms could be considered descriptive theory in the manner of Meleis’ definition”. Therefore, if one develops theory using a descriptive focus to understand and explain human processes, one is developing theory that is termed descriptive. A growing body of literature suggests that the nursing profession should also strive to develop descriptive theory, valuing this way its importance to clinical practice (McEwen and Wills 2006; Wilson 1995; Grossman and Hooton 1993; Ingram 1991).

Plager (1994, p81) was sceptical about the predictive abilities of descriptive theory by asserting that knowing as understanding in a particular context is limited in its predictive ability. However, at the same time Plager (1994) attempted to reclaim the predictive ability of descriptive theory by asserting that “gaining a better understanding of what are the issues and concerns may help to anticipate future events for a person or family and aid in an understanding of the significance the person or family gives them” (p81).

If one compares these textual forms intended to influence understanding to Meleis’ definition of prediction, one recognises that they will not indicate when a phenomena will occur and when it will not occur in an ‘if, then’ manner. However, understanding the issues and concerns of an individual in a particular situation, and the significance he/she gives to those issues and concerns, may help one to anticipate future significant events, should similar situations occur with the same person (Van der Zalm and Bergum 2000, p214).

What this study has managed to develop is a descriptive theory that does not claim to predict phenomena in an “if, then” manner as Van der Zalm and Bergum clearly have pointed out. However, with the identification of the attributes of quality nursing care and the description of the circumstances under which it occurs by the informants in the narratives, some predictability of the produced theory is achieved. The results of hermeneutical inquiry according to Van der Zalm and Bergum (2000) also have anticipatory and sensitising abilities. Therefore the theory that is been described here should be read in the light of these limitations.

A theory of quality nursing care

Even though it is difficult, as was discussed above, to produce a theory through this specific philosophical approach, it is possible to describe a phenomenon, which in this case is that of “quality nursing care”, hence, generating descriptive theory. Therefore what is being attempted in this chapter is to put together the findings of this study in an abstract way in order to reach an understanding of the phenomenon by identifying its components; and identifying some of the circumstances under which it occurs as Meleis asserts (2006, p44). The principles of hermeneutic phenomenology served as the basis for this attempt, and during this every effort has been made not to “betray” the fundamental traditions of this philosophical paradigm and specifically the ideas of Ricoeur.

Therefore, according to the lived experiences of the informants, seven attributes of the concept of quality nursing care were identified, based on which this concept is interpreted. The seven attributes include a) availability and accessibility issues, b) issues of communication and emotional support, c) issues of information giving, d) providing care by competent nursing staff, e) providing spiritual and religious care, f) issues of shared decision-making and g) family presence and involvement. The study also emphasised the influence of the cultural context on the conceptualisation of the attributes. Therefore, ethnohistory holds a central place on the produced theory¹³⁰ and here lies the reason why the lived experiences were interpreted in the light of the ethnographic characteristics of the informants.

Based on the philosophical paradigm that underpins this study, I would comment that despite the fact that this study has managed to clarify what the concept of quality nursing care means for patients, advocates and nurses, it illustrated that a simple and universal interpretation does not exist. It is evident that the informants found it a difficult task to interpret this concept in just one sentence. They rather provided extensive descriptions of what they perceived as quality nursing care and what this entitles. This evidence highlights the importance of *language* as a principle of hermeneutic phenomenology. It

¹³⁰ See appendix B – Figure 6: A Schematic presentation of the theory

also stresses the importance of using simple language as close to the lived experiences as possible. What can also be argued about the findings is that it brings closer to understanding of quality nursing care than studies which have been translated in a language different than that of the informants, something which was done by my predecessors who provided simplistic definitions of quality nursing care, “violating” in a way the principle of language. Therefore, the findings of this study are presented in the form of the interpretations that the informants have provided in the narratives selfsame.

Furthermore, I would like to speak about the over-conceptualisation of the term “quality” in terms of nursing and more broadly in health care. It was shown from the study’s findings that the informants hold different perspectives of what constitutes quality nursing care and quality health care. Even if previous researchers have used these two terms often interchangeably these turn out to have different meanings, complementing therefore, the work of Oermann (1999), Oermann et al. (2000) and Irrurita (1996) who stressed the difference between the two concepts. The informants pointed out that quality nursing care is a specific concept which should include and be evaluated based on those actions and responsibilities held by the nurse when caring for the patient. This finding highlights the fact that nursing being a separate and unique science holds an autonomous place in health care. A paradox however rises at this point, while nursing being an independent paradigm can not be separated from the health care as whole. Perhaps this might raise concerns; however, in order for the reader to grasp the whole idea is to interpret these claims in terms of the principles of the hermeneutic circle as this study has done. Therefore, nursing should be viewed as one *part* of the health care which represents the *whole*. As Ricoeur asserts understanding occurs through the dialectical movement between the parts and the whole, similarly understanding of quality nursing care can occur in the light of the wider phenomenon of quality health care, and as such should be interpreted.

The type of theory that was generated from this study, poses by definition certain limitation concerning the status of the guidelines that were also produced as a way of transforming theory into the clinical setting. Therefore, these guidelines are not

predictive in nature; that is they can not guarantee that quality nursing care will be achieved if every attribute of quality is addressed. However, what is important is to know and perhaps most importantly understand those issues and concerns of the patient with cancer when he/she is being cared for. Knowing and understanding can enable the health professional and specifically the nurse to act upon these concerns. What it is aimed through the guidelines is to sensitise and inform the nurses on specific issues and concerns in relation to patients which are based on empirical evidence.

The need for guidelines

The field of cancer care has grown rapidly in Cyprus in the last five years. However, there was great variability in relation to the understanding of “quality nursing care”. It could mean that nursing care was provided by competent specialised nurses, or that the patient was cared for holistically, having his/her physical, spiritual, emotional and social needs satisfied.

As the field grew, the need for guidelines to work toward eventually became obvious to nurses. This is evident in the statement by the Chief Nursing Officer’s declaration that nursing needs to be planned and evaluated using standards and guidelines (Tapakoude 2001). This field of nursing is at such an early stage of development, that nurses should be planning a set of guidelines, to address and support nursing practice. Therefore, these guidelines have been created as a response to the Nursing Division in Cyprus for attaining quality (Tapakoude 2001). These guidelines try to assure a higher level of quality for a growing number of cancer care programs across the country, some level of consistency among and between them, and a set of criteria against which programs can compare themselves.

This dissertation has many of the classical characteristics of research that will not influence practice: its presentation as a PhD thesis will reduce its accessibility to clinical nurses, it is highly theoretical in nature, and its implications for practice are not readily apparent. The guidelines presented here are an attempt to resolve this difficulty by relating the research to nursing practice. It is evident in the literature that the gap

between scientific evidence and clinical practice can be significantly reduced by guidelines (Wallin et al. 2000; Duff et al. 1996).

Although there is clearly a need to address guidelines of nursing care in cancer care departments, and despite the fact that research is often not related to practice, a critic might still argue that the development of guidelines is inappropriate in a thesis that is grounded in hermeneutic phenomenology. The critic might also argue that individuals hold various perspectives of what constitutes quality of nursing care, and might condemn the guidelines presented below for being based on one person's interpretation of narratives with a small number of patients with cancer, their advocates and the nurses. However, the hermeneutical grounds of this study reject these criticisms. The hermeneutical emphasis on the social, historical and contextual nature of knowledge and understanding is reflected throughout the present study, in the assumption that the quality of nursing care can not be reduced to a list of a-historical characteristics that can be isolated, described, measured and manipulated. It should therefore be understood that the guidelines are not intended as a formula, or as a "cause" whose "effect" would be the automatic restitution of the quality of nursing care of the patients, as this view would contradict the entire thrust of this dissertation. It is accepted that care must be taken when extrapolating the findings of a qualitative study that incorporates the views of a particular group of people, expressed at a specific time and place. However, the guidelines also incorporate the findings of a substantial body of empirical literature, and are firmly grounded in a philosophical tradition.

The nature of guidelines

The World Health Organisation defines guidelines as sets of steps which can be taken in performing a task, or implementing a policy and the manner of so doing. Guidelines are tools to assist in a process and towards an outcome (WHO 1998). This definition coincides with one taken from the Oxford English Dictionary: a principle or criterion guiding or directing action (OUP 2002).

The National Institute for Clinical Excellence (2007) defines guidelines as recommendations for the care of individuals in specific clinical conditions or circumstances – from prevention and self-care through primary and secondary care to more specialised services. The European Commission based on Field and Lohr (1992) recommendations also proposes a core definition for guidelines. They are defined as systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.

These definitions however, raised concern as to the nature of this study's findings and whether these can indeed be labelled as "guidelines". I am aware that clinical guidelines in its traditional sense refer to systematically developed advisory statements created according to validated methodologies and relate to evidence-based healthcare (WHO 2003; Field and Lohr 1990). Even though this was not the approach that I have taken in this thesis, I can still claim that the end product of the study consists of a set of clinical guidelines which aim at improving the quality of the nursing care provided to patients even though not in their traditional/classic sense. My argumentation was based on the fact that the end product of this study was methodically developed based on the amalgamation of data deriving from different independent sources (empirical data), from a thorough review of the literature, from a review of the current quality efforts of the Cyprus Ministry of Health to attain nursing care quality and from a review of the ethnohistoric background of the informants. Therefore, what has been achieved by this study was the development of an explicit approach to specific areas of the nursing care, which can be improved through simple actions suggested by patients, advocates and nurses. In no case are these actions definite or absolute. These can be further developed through clinical testing and by reviewing the views of the patients, advocates and the nurses. This circular process has also been highlighted in the literature (EONS 2007; WHO 2003).

Method by which the guidelines were developed

The guidelines presented below are validated by the research that is described in the earlier chapters of the thesis. The process of converting general recommendations for

practice into guidelines developed in three phases. This study reinforced the importance of “getting the basics right” and of improving the patient’s experience of being cared for cancer. The wide participation of informants has enabled me to identify best practice and to improve nursing care through acquiring the patients’, advocates’ and nurses’ views. They agreed and described good quality nursing care and best practice. This resulted in best practices covering seven areas of nursing care:

1. Receiving care in easily accessible cancer care services.
2. Being cared for by nurses who effectively communicate with them and their families and provide emotional support.
3. Being empowered by nurses through information giving.
4. Being cared for by clinically competent nurses.
5. Nurses addressing their religious and spiritual needs.
6. Being cared for in a nursing environment which promotes shared decision-making.
7. Patients being with and involving the family in the care.

It should be recognised that these practices are interrelated. For example, there are elements of “*being cared for in a nursing environment which promotes shared decision-making*” that link with “*being empowered by nurses through information giving*”. In the second phase, the elements consisting of each of these best practices were retrieved from the data explication process, highlighting the aspects of the care that the guidelines aim at. These aspects specifically referred to problems faced by patients and their families when being cared for cancer. They also referred to problems experienced by nurses when caring for patients with cancer and their families in clinical practice. These aspects consisted of not only the most highly reported elements but also those that were equally reported by patients, advocates and nurses. Following, is a list of the various elements of each of the best practices that cover the seven areas of the nursing care:

Receiving care in easily accessible cancer care services

- Resources availability in cancer care.
- Easy access to cancer care services.
- Care provided independently of any geographical characteristics.
- Accessibility takes into consideration the individual's preferences and ability to access the service so that the burden experienced by the patient and his/her family members due to transportation issues can be avoided and their presence with the patient promoted.

Being cared for by nurses who effectively communicate with them and their families and provide emotional support

- Knowing and emotionally supporting the patient.
- Effective communication can promote individualisation.
- Avoidance of hermetic communication or "routine communication agendas".
- Overcoming the belief that patients do not understand technical terms.
- Avoidance to engage in meaningful communication.

Being empowered by nurses through information giving

- Proximity and trust enables the patient to be informed by the nurse.
- Promotion of person-tailored information.
- Overcoming organisation and regulation restraints.
- Addressing issues of power between health care professionals.
- Providing meaningful information to the patient that is clear.
- Overcoming the belief that the patients can not or do not want to cope with information.

Being cared for by clinically competent nurses

- Competent nurses have professional knowledge and technical competence.
- Clinically competent nurses meet patient's physical needs.

- Competency extends to include qualities such as caring behaviours, comforting, supportive and being there for the patient.
- Competent nurses can promote the feelings of trust and safety.
- Provision of more opportunities to gain specialty in cancer care.

Nurses addressing their religious and spiritual needs

- Assess and respect patient's religious and spirituals needs.
- Address patient's spiritual needs and make arrangements to also have his/her religious needs met.
- Continuity of spiritual life after hospitalisation.
- The nurse with the priest's support can meet the patient's spiritual needs.
- Overcoming negative perceptions and beliefs about priests visiting the patients on the ward.

Being cared for in a nursing environment which promotes shared decision-making

- Sharing professional knowledge
- Respecting the patients' knowledge and appraisals.
- Empowering patients through promoting their participation in decision-making processes.
- Informing the patient to allow participation in decision-making.
- Advocating for policy to promote SDM.
- Overcoming cultural barriers to implementing SDM.

Patients being with and involving the family in the care

- Promoting family presence and its involvement in the care.
- Family assuming a supportive role for the patient.
- Avoidance of strict visitation policies.
- Promote family-centre approach

In the final phase, the best practices along with their consisting elements that were shown by the research to be associated with quality nursing care were amalgamated to form the final guidelines for clinical practice. Through the given list of guidelines, 1

illustrate the general approach and indicate the form that guidelines take. Explicitly, guidelines are presented in tables. Each table is divided in three parts. In the first column the guideline statement is presented, the second column represents the actions recommended to the nurse in order to address the guideline and finally in the third column the intended patient benefits are presented.

Table 7.1: Guideline – Receiving care in easily accessible cancer care services.

Guideline	The nurse:	The patient:
<p>The nurse deals with the factors that fall under his/her control in order to facilitate access to cancer care services.</p>	<p>identifies those patients belonging to the perceptive categories and who might have access problems.</p> <p>takes measures so that the hospital and the Ministry of Health are informed about the patient's access problems.</p> <p>can arrange for the patient to be referred to other cancer centre, which he/she can better access.</p> <p>can arrange patient's visits to the hospital for treatment in collaboration with the patient.</p>	<p>feels that his/her problem accessing the service can be known to the management through the nurse.</p> <p>is given the choice to be referred to a specialised cancer centre which he/she can access more easily.</p> <p>influences the care planning to suit his/her ability to access the service.</p>

Table 7.2: Guideline – Communicating with patient and families

Guideline	The nurse:	The patient:
<p>The nurse establishes healthy communication with the patient and the family.</p>	<p>applies in practice ways of setting up effective communication channels.</p> <p>applies non-verbal communication skills in an effort to communicate with the patient and family.</p> <p>involves the family in the emotional support of the patient through effective communication.</p> <p>is using appropriate language to convey information to the patient and family.</p> <p>assesses whether the patient is able to understand the meaning of the provided information.</p> <p>does not limit communication with the patient based on a “routine communication agenda”.</p> <p>communicates with the patient and his/her family to better “know” them.</p>	<p>values the ability being able to communicate with the nurse.</p> <p>values the non-verbal ability of the nurse to identify his/her unvoiced needs, desires or worries.</p> <p>receives emotional support from his/her family.</p> <p>feels able to speak to and being understood by the nurse and vice versa.</p> <p>has his/her ability to understand technical terms not undervalued or overvalued.</p> <p>has the opportunity to freely ask questions or clarifications from the nurse.</p> <p>feels comfortable to open up to the nurse. His/her personal characteristics are conveyed to the nurse who allows a more personalised care to take place.</p>

Table 7.3: Guideline – Being empowered by nurses through information giving.

Guideline	The nurse:	The patient:
<p>The nurse adequately informs the patient in relation to his/her nursing care.</p>	<p>evaluates whether the patient and family desires to be informed and respects their preferences.</p> <p>informs the patient as part of the nursing care plan.</p> <p>uses person-tailored information to match the patient's educational background and individual needs.</p> <p>avoids giving limited information which can be vague and misleading.</p>	<p>can also seek information from the nurse and not just his/her physician.</p> <p>receives meaningful information and not simply general information.</p> <p>has his/her preferences respected by the nurse.</p> <p>influences the nature and amount of the information he/she receives from the nurse.</p>

Table 7.4: Guideline – Caring by clinically competent nurses

Guideline	The nurse:	The patient:
<p>The nurse caring for patient with cancer is clinically competent.</p>	<p>demonstrates caring behaviours. He/she is also comforting and supportive and being there for the patient.</p> <p>has the professional knowledge and technical competence to care for the patient.</p> <p>develops his/her technical skills and knowledge in order to meet the patient's physical needs.</p>	<p>has his/her physical needs being satisfied by the nurse.</p> <p>feels safe when cared for by clinically competent nurses.</p> <p>receives support and comfort from the nurse whenever he/she needs it.</p> <p>experiences a sincere concern expressed by the nurse when being cared for.</p>

Table 7.5: Guideline – Nurses addressing patients’ religious and spiritual needs

Guideline	The nurse:	The patient:
<p>The nurse provides spiritual and religious care to the patient.</p>	<p>plans and delivers the care in accordance to the patient’s needs.</p> <p>addresses more than simply the patient’s physical needs but also his/her religious and spiritual needs.</p> <p>supports patient’s search for existential meanings within the experience of having cancer and with reference to God.</p> <p>promotes priest’s presence on the ward and works together with him to meet the patient’s spiritual and religious needs.</p>	<p>is cared for in a holistic way so that his/her spiritual and religious needs are also addressed by the nurse.</p> <p>receives care as a human being and feels that attention is also given to his/her mind and spirit.</p> <p>can rely on the nurse and the priest to have his/her spiritual and religious needs met.</p>

Table 7.6: Guideline - Being cared for in a nursing environment which promotes shared decision-making

Guideline	The nurse:	The patient:
<p>The nurse cares for the patient in a nursing environment which promotes patient participation in decision making processes.</p>	<p>evaluates the willingness of the patient to participate or not in his/her care decisions.</p> <p>shares professional knowledge – he/she informs the patient about the treatments, medication, diagnostic examinations, laboratory results and everything that is related to the care.</p> <p>takes into consideration the patient’s knowledge and experience in the decision-making process.</p> <p>provides the patient with all the necessary information which will allow him/her to participate in his/her own care.</p> <p>plans aspects of the nursing care in collaboration with the patient to better suit the patient’s needs.</p> <p>provides decision aids to the patient in order to facilitate SDM.</p>	<p>has the choice to participate or not in his/her care decisions.</p> <p>is an active informant to his/her nursing care.</p> <p>has the information to allow him/her take the decisions that relate to his/her care.</p> <p>possession of knowledge, experience and appraisals are heard and utilised in his/her care plan by the nurse.</p>

Table 7.7: Guideline - Nurses being with and involving the family in the care

Guideline	The nurse:	The patient:
<p>The nurse adopts a family-centred approach to nursing care.</p>	<p>respects the patient's need to have his/her family close.</p> <p>promotes family presence and involvement in the care of the patient with the implementation of a flexible visitation policy.</p> <p>respects the family's willingness to be with and involved in the care.</p> <p>involves family in information exchange and participation in decision-making.</p>	<p>has his/her family close when being cared for.</p> <p>feels comforted from the presence and emotional support from his/her family.</p> <p>can take decisions related with his/her care with the family reciprocally.</p>

PART 5

CHAPTER 8

LIMITATIONS OF THE STUDY, RECOMMENDATIONS FOR FURTHER RESEARCH AND CONTRIBUTION TO KNOWLEDGE

In this final chapter of the thesis I undertake an assessment of the limitations of the research, and make recommendations for further work. The word “limitation” is interpreted to mean “boundary”. Consequently, this section assesses both the strengths and weaknesses of this research.

One of the strengths of the dissertation is its discussion of the implications of hermeneutic phenomenology for the conduct and analysis of qualitative interviews. This section provides a useful bridge between the theoretical literature of Ihde (1971), Palmer (1969), Kearney (2006) and others who discuss the principles of hermeneutical research, and the methodological literature of qualitative analysis.

In keeping with the aims of qualitative research, the samples for this study were not selected based on the need to generalise findings, but by the desire to achieve rich data about the experience of being treated and providing care for cancer. However, the samples were selected from all the major hospitals and cancer associations in Cyprus providing, in a statistical sense, some representation. The generalisability of this study does not derive from the representativeness of the sample, but from the concepts (such as quality nursing care) and guidelines that may well be relevant to other settings and patient groups.

A strength of this study was also the participation of two experienced researchers in the construction and translation of the data collection tools and the data analyses procedures, ensuring that the appropriate decisions were made, and that the research procedures were correctly applied.

Finally, the research is unusual in that it relates the findings to clinical practice. Although the guidelines that are presented in the previous section are unremarkable in

themselves, they are valuable because they are grounded in and justified by a coherent philosophical approach.

If an assessment of the limitations of this study were to be based on the normal standards of positivist research (quantitative research), it would identify as problematic the small sample size, that the sample is unrepresentative in a statistical sense, and that the study lacks objectivity because it displays the influence of my perspective. However, these criticisms are inappropriate in a hermeneutically grounded study that has, by definition criticised, the basic assumptions of positivism. For the sake of completeness and clarity, certain limiting features of the study are identified in the following list. Some of the items on this list are the inevitable consequence of the hermeneutical foundations of the research, whilst others can be attributed to the researcher.

- The guidelines do not represent a list of universally valid, a-historical principles which will ensure the quality of nursing care in cancer care settings.
- I have both criticised and assumed the continuing existence of the institutional pattern of care which is based on the bio-medical model of care.
- This study does not make the assumption that care is solely delivered by the nurse. I have acknowledged the fact that care is a many-sided concept that its provision also involves other health professionals and sometimes the patients' family. It was my conscious choice only to explore the aspect of the care that was provided by the nurses.
- The analytical procedures have been described in a rather tentative way.
- The research is non-reproducible.

Recommendations for Further Research

Three ideas for further research are given. First, it would be useful to develop more practice guidelines of the kind that are described in chapter 7. These could then be validated through application in the practice setting.

Second, it would be possible to take some of the ideas that are presented in chapters 6 and develop them in more detail. For instance, the meanings that spiritual needs have for patients with cancer were discussed. Researchers have so far focused on the issue of spirituality in more general terms rather than focusing on patients with cancer. Nursing research which focused on the meanings of the spiritual needs for patients with cancer would therefore be a valuable addition to the literature.

Third, it would be possible to explore the perspectives of family members that take upon the role of the informal caregiver in relation to “quality nursing care” and other aspects of the care highlighted in chapter 6. The study has shown that family plays an important role when it comes to the care of patients with cancer and it would be beneficial to investigate the burden that the role of the informal caregiver has.

Original Contribution to Knowledge

This piece of work is unique in many ways and innovative in others with substantial contribution to the field. Through this study I have managed to provide interpretations of the term quality nursing care (theory) as this was conceptualised by patients, advocates and nurses. A meaningful communication on this issue implies a common understanding of this phenomenon. It implies an essential meaning we must all be familiar with in order to discuss “quality nursing care”. As the hermeneutic nature of the study prevents me from speaking about “consensus terms”, what I have done as a means to overcome this barrier was to draw upon a shared familiarity with the world in which quality nursing care takes place. This is important in order to use “definitions”, “concepts” and “terms” that are equally understood by the patient, advocates and nurses. This way the

nurse can better care for the patient and towards the same goals in relation to nursing care.

The theoretical and methodological framework that was applied in this study, that of hermeneutic phenomenology, was innovative for researching the topic under investigation offering a new insight to the field. As part of this method, the “lived experiences” of the informants were used as the primary source of the research data. This framework allowed the consideration of aspects of the informants’ ethnohistoric background in the interpretation of the research data and the amalgamation of these into the findings. With the application of an innovative data analysis method inspired by the Interpretation Theory of Paul Ricoeur but modified to suit the nursing paradigm which has the person in its focus, the findings were not limited to textual interpretations but the people in the play were also taken into consideration. The application of this approach to the nursing research along with the explanation of every step of the research process, offers a valuable example and an invitation to other nurse-researchers to apply this philosophical approach to other nursing studies.

The review of the relevant literature revealed that researchers quite often have come up with definitions of what constitutes quality nursing care whilst taking for granted several assumptions about this issue. They often assume that patients and nurses hold similar perspectives on this issue. Moreover the vast majority of the available definitions were developed merely by seeking either the perspectives of the patients or the nurses unlike this study where the nurses had the opportunity to respond to the opinions, concerns and problems raised by the patients and their advocates at the time that these were expressed. Therefore the materialisation of the findings derived through the discourse between the informants - a process suited for the hermeneutic tradition. Another assumption made by researchers is that the issue of culture of the informants is not important to the topic under investigation and therefore not being considered in these studies implying that these definitions are or can be a-historical or universally valid. This study however, makes none of these assumptions and took these into consideration in the process of developing the study, retrieving the research data and interpreting them.

In terms of the guidelines that have been produced as part of this research, the nursing care that is provided in cancer care departments can be improved. The most important aspects of the care that were identified as problematic by the informants can be addressed through simple measures which were proposed by the informants. What is more important is that these guidelines are characterised by their generic nature which allows for these to be applied in settings other than merely the cancer care departments.

Finally, this study has brought to the foreground the need for returning back to the basics of the nursing care we provide to patients. Issues which have for years been taken for granted by the nurses, such as the importance of communicating with the patient and his/her family, were now validated against a wealth of empirical data deriving from this study. It seems that we have been overwhelmed by a myriad of responsibilities and tasks (often not even nursing tasks) that we have "taken-for-granted" the obvious/the intended in relation to the care. We all know we have to do certain things for our patients but a lot of time for various reasons we fail to do so. This study illuminates these aspects of the care and offers possible ways to tackle the problems arising as a result of not adequately addressing these aspects of the care.

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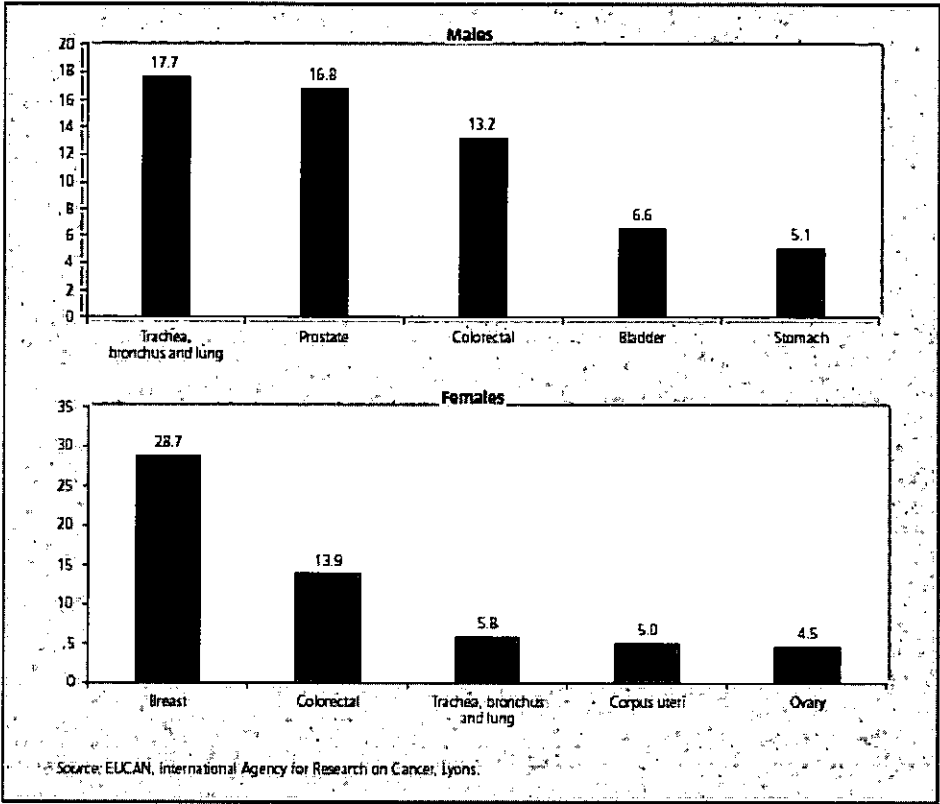
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Appendices

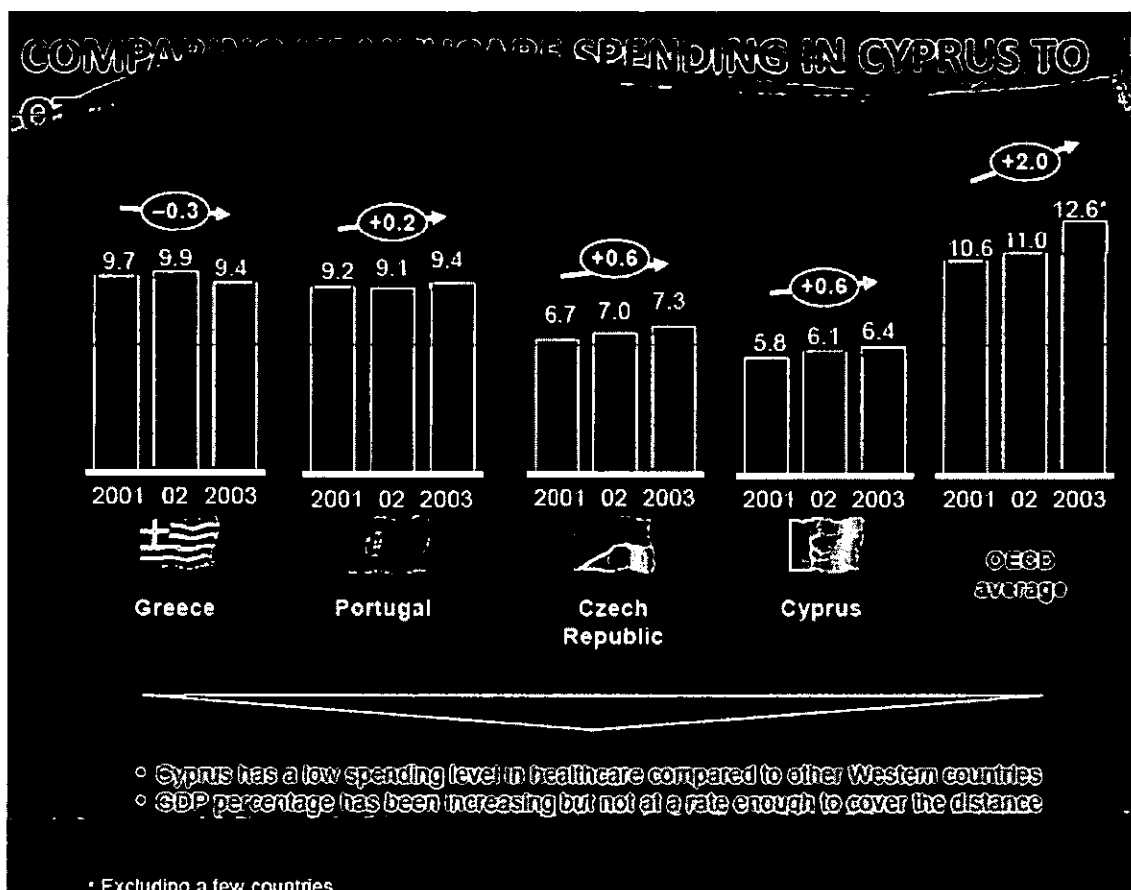
Appendix A

Chart 1: Percentage of specific cancers over total number of cancers in the 15 EU countries



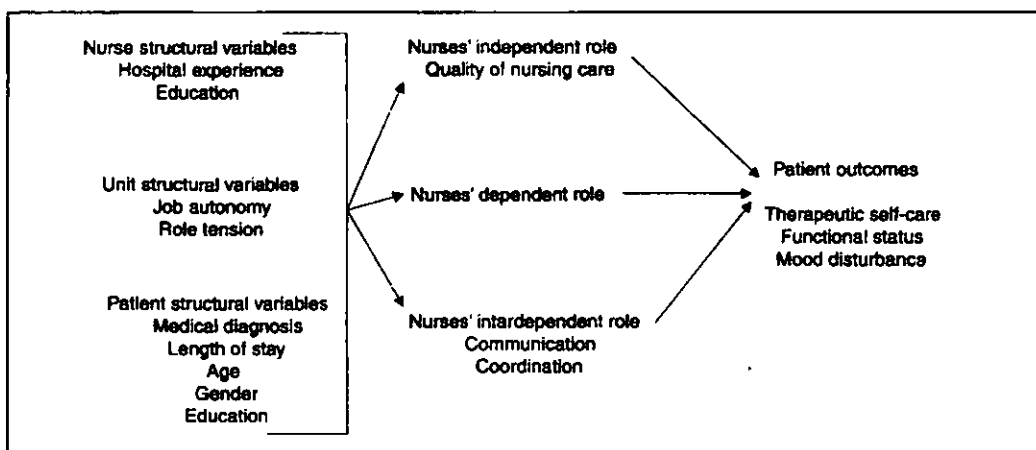
Source: EUCAN, International Agency for Research on Cancer, 1997.

Chart 2: Comparing healthcare spending in Cyprus to other countries



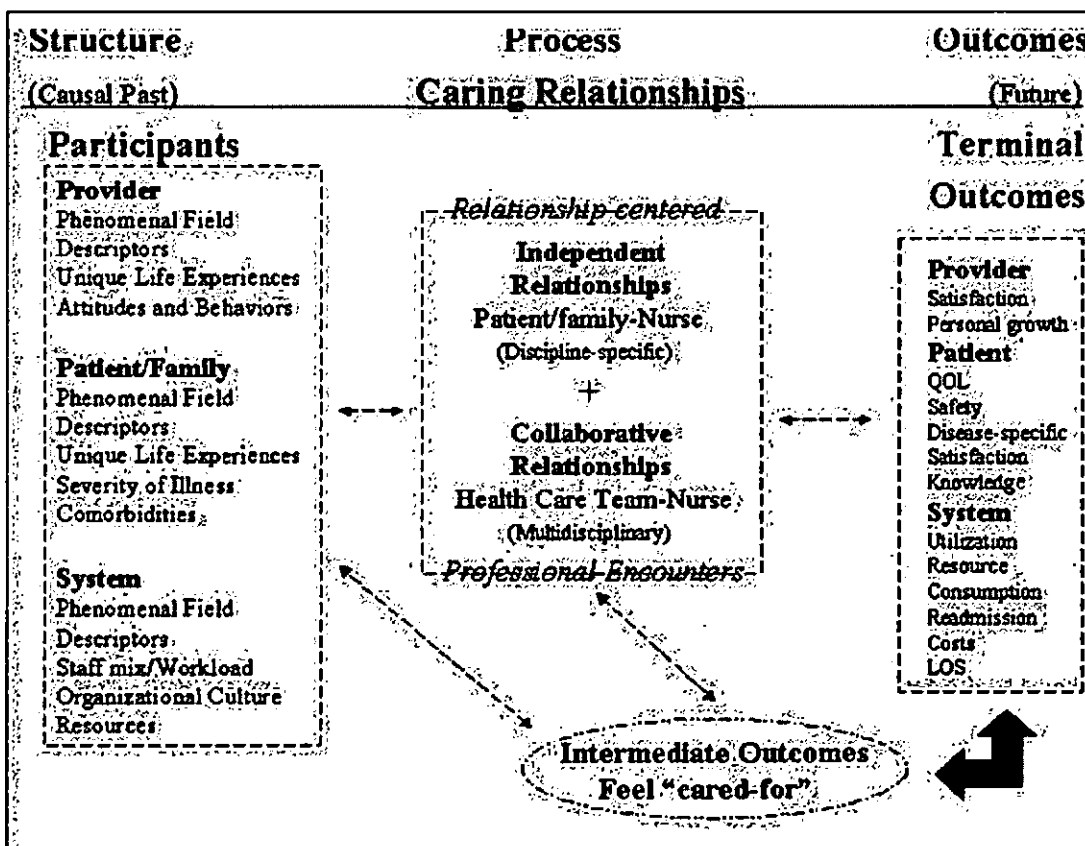
Source: Health Insurance Organisation. (2007b). National Health System – Strategy. Retrieved from <http://hio.org.cy/gr/strategy.html>.

Figure 1: Irvines and Sidani “Nursing role effectiveness model”



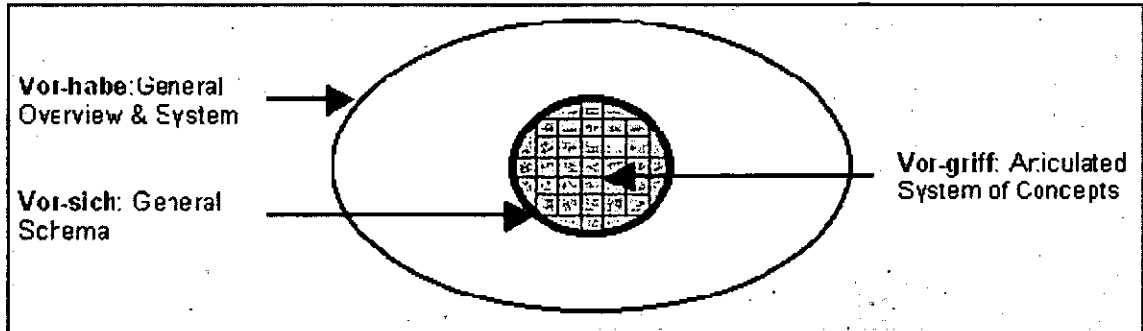
Source: Irvine, D., and Sidani, S (2002) An Empirical test of the Nursing role effectiveness model. *Journal of Advanced Nursing*, 38(1), p29-39.

Figure 2: The Quality-Caring Model



Source: Duffy, J & Hoskins, L.M. (2003). The Quality-Caring Model: Blending Dual Paradigms. *Advances in Nursing Science*, 26(1), p81.

Figure 3: Fore-having (*Vorhabe*), 'fore-sight' (*Vorsicht*) and 'fore-conception' (*Vorgnff*) of the thing.



Source: Demeterio, F.P.A. (2001). Introduction to Hermeneutics. *Diwatao*, 1(1)

Figure 4: Gadamer's idea of 'Fusion of Horizons'

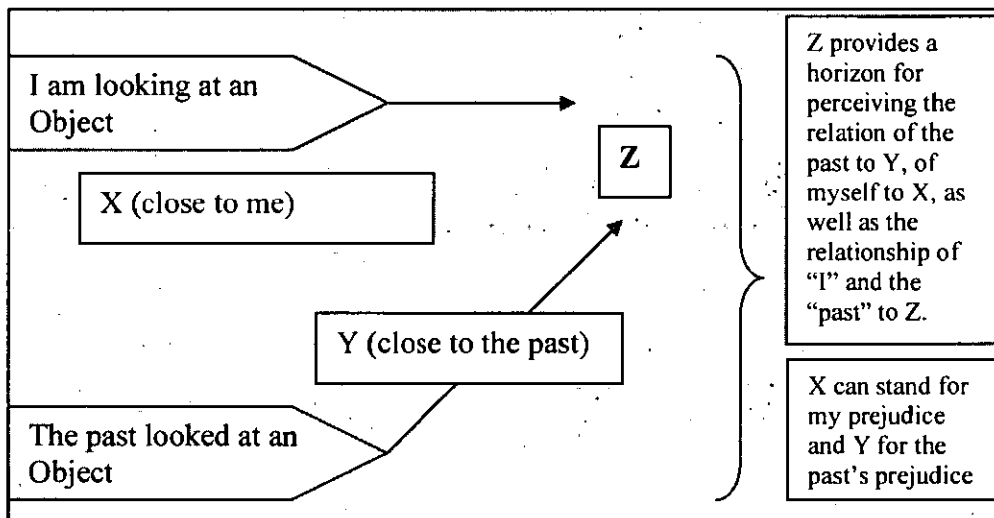
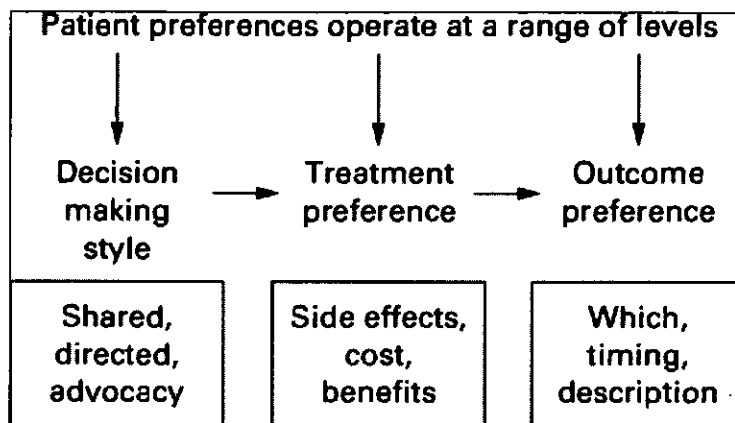
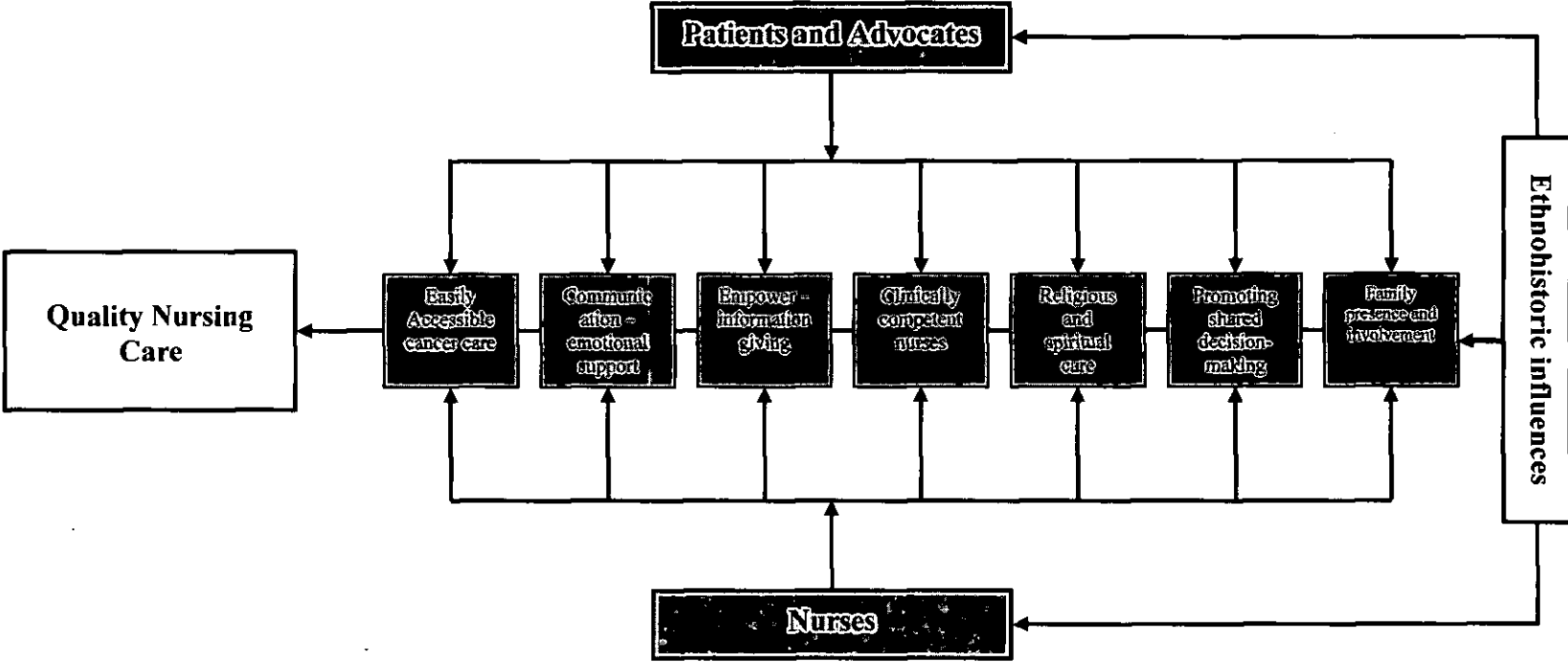


Figure 5: Patients' preferences operate at a range of levels



Source: Bowling, A, & Ebrahim, S. (2001). Measuring patients' preferences for treatment and perceptions of risk. *Quality Health Care*, 10(suppl 1): pi6.

Figure 6: Schematic presentation of the Theory of Quality Nursing Care



Appendix B

Diagram 1: Cyprus Health Care System (Post-Reforms)

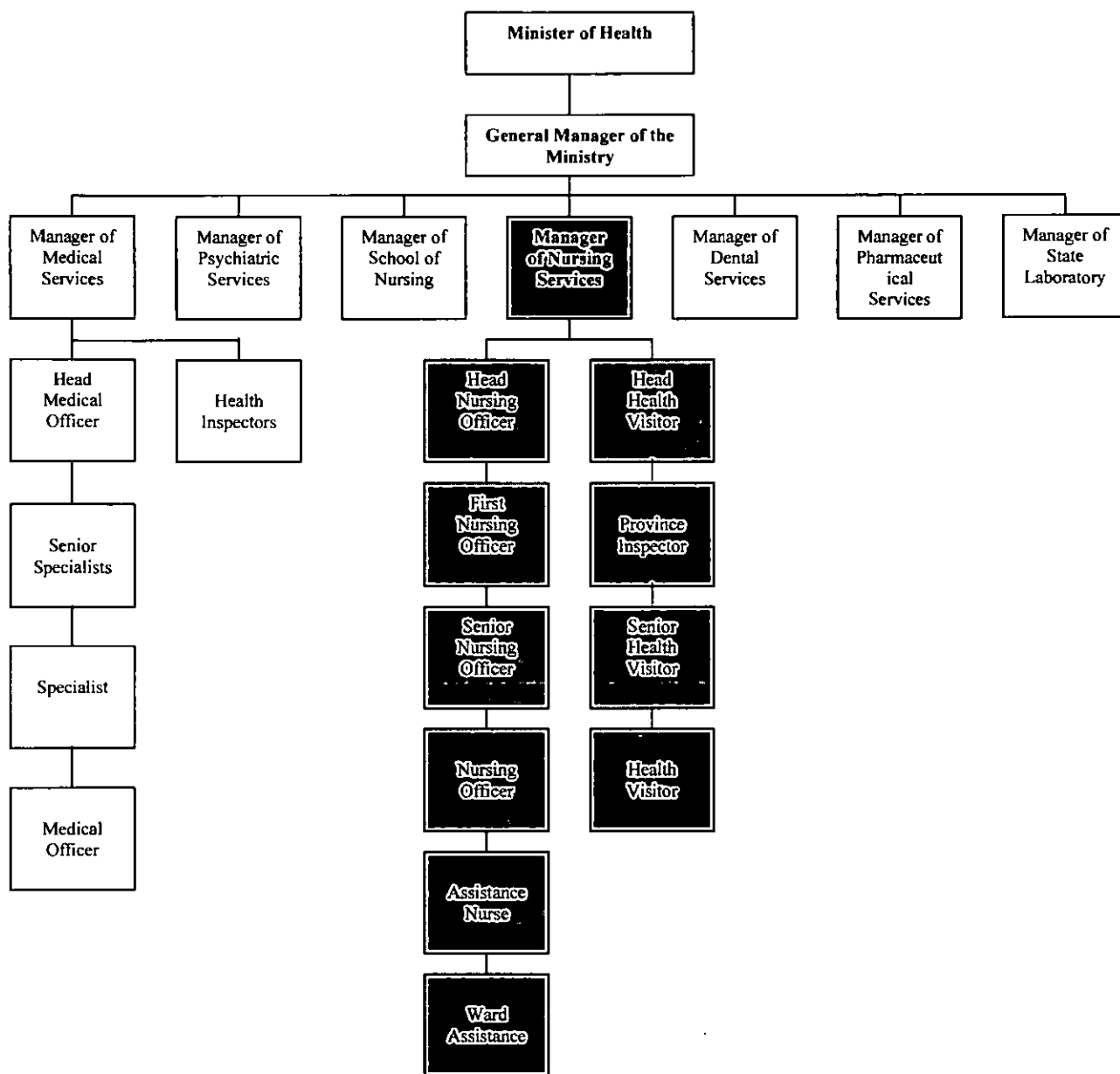
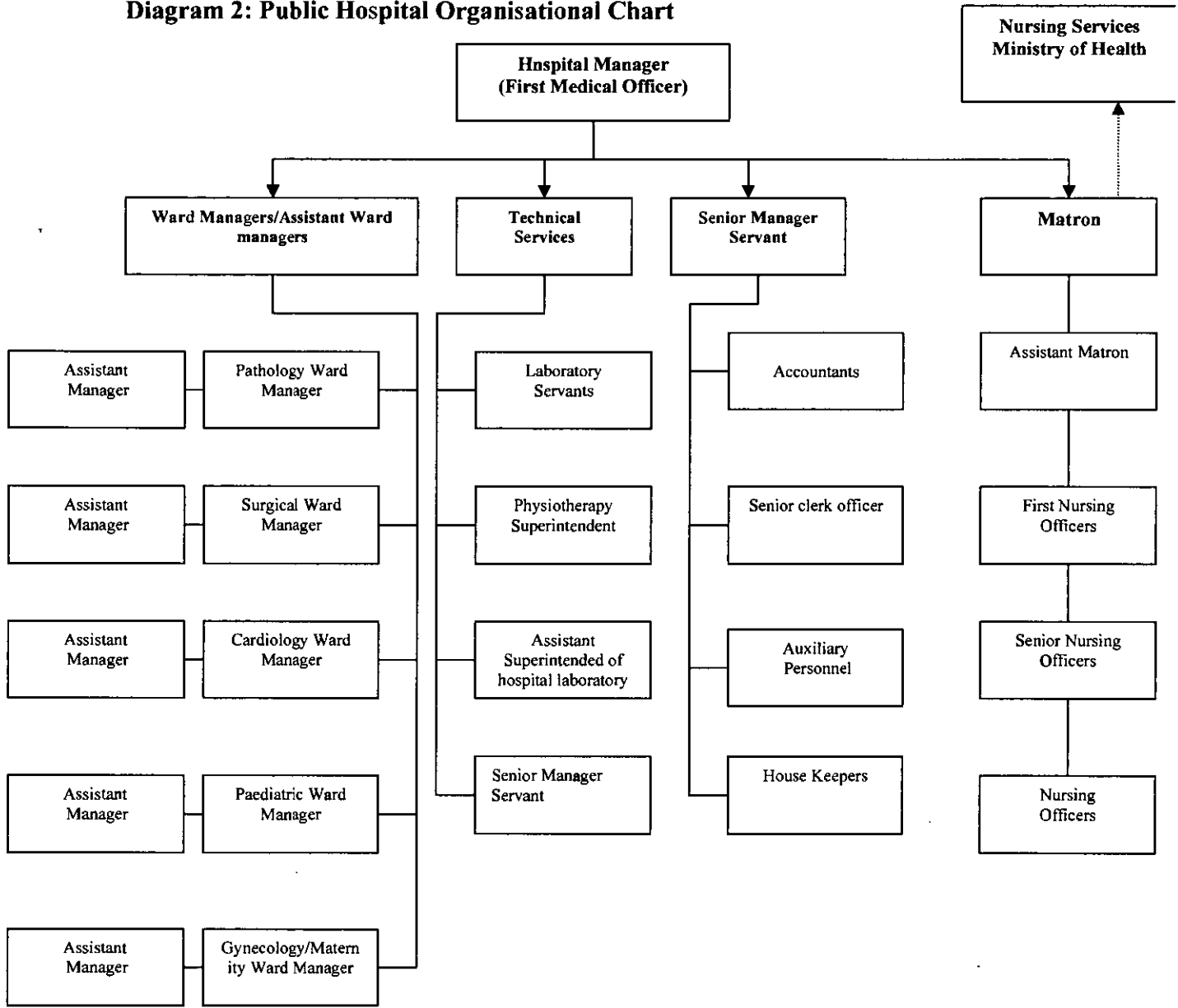
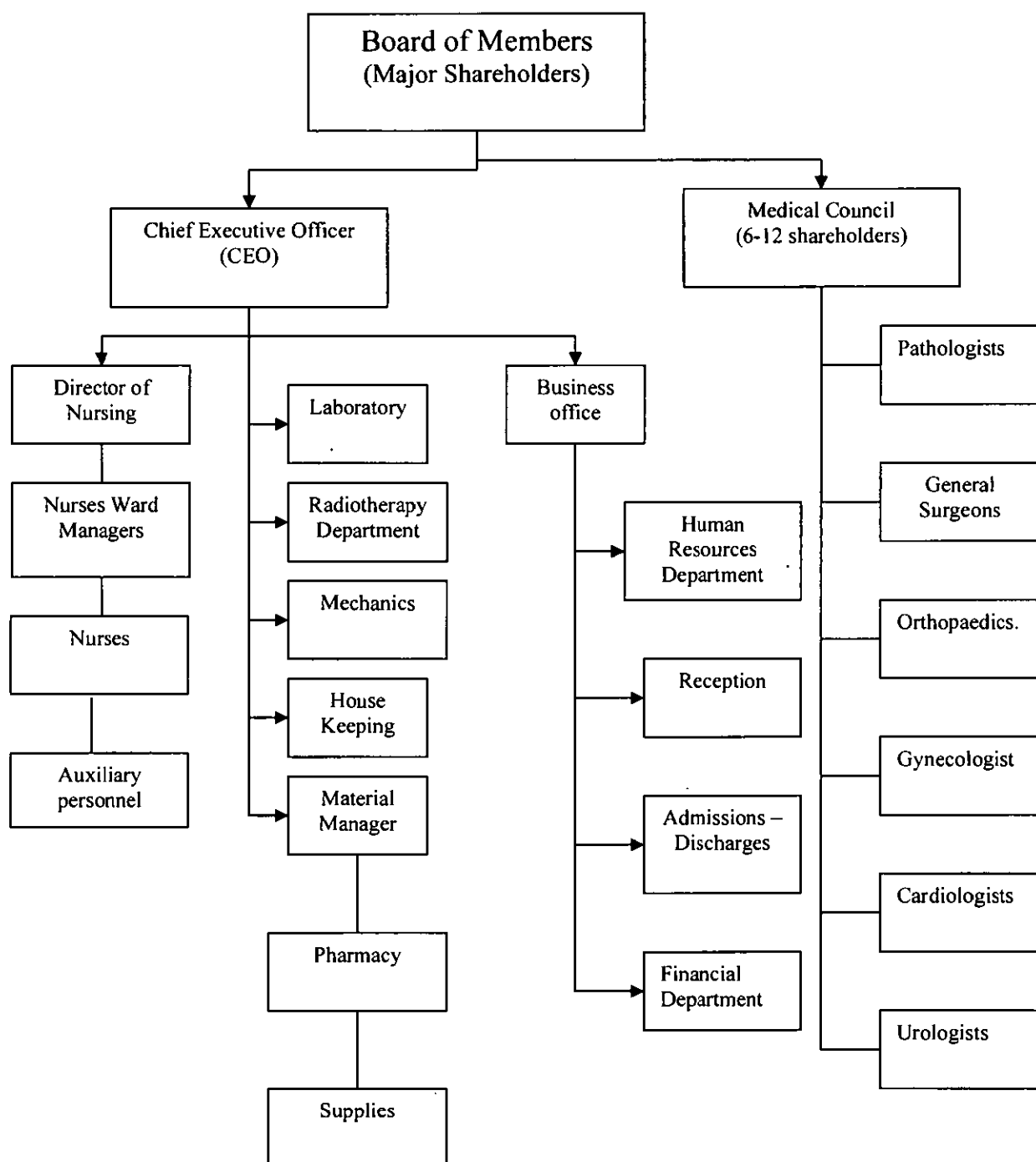


Diagram 2: Public Hospital Organisational Chart



Source: Charalambous, A & Socratous, S. (2006). Public Hospital Vs Private Hospital. *Cyprus Nursing Chronicles*, 7(3), p21

Diagram 3: Private Hospital Organisational



Source: Charalambous, A & Socratous, S. (2006). Public Hospital Vs Private Hospital. Cyprus Nursing Chronicles, 7(3), p22.

Appendix C

Table 1: Donabedian's Quality of Medical Care Model

Structure	Process	Outcomes
System characteristics	Technical style	Clinical end points
Provider characteristics	Interpersonal style	Satisfaction with care
Patient characteristics		Functional status
		General well-being

Source: Donabedian, A. (1988). Quality assessment and assurance: unity of purpose, diversity of means. Inquiry, 25, p173-192.

Table 2a: National Health Expenditure

<i>£ εκατ.</i>								<i>£ mn</i>
Ανάλυση	1998	1999	2000	2001	2002	2003	2004	Analysis
ΔΗΜΟΣΙΟΣ ΤΟΜΕΑΣ	114,5	125,9	137,2	151,2	175,6	215,4	214,6	PUBLIC SECTOR
(1) Ακαθάριστες επενδύσεις	6,4	9,5	10,8	11,1	17,8	24,2	24,9	(1) Gross capital formation
(2) Αμοιβές υπαλλήλων	69,7	73,7	79,2	85,2	90,8	106,2	108,3	(2) Compensation of employees
(3) Κοινωνικές εισφορές και παροχές	9,8	9,8	11,9	12,6	15,5	16,6	15,8	(3) Social benefits
(4) Ενδιάμεση Ανάλωση	26,8	30,3	32,2	37	44,8	62,5	59,3	(4) Intermediate consumption
(5) Λουπές τρέχουσες μεταβιβάσιες	1,8	2,6	3,1	5,3	6,7	5,9	6,3	(5) Other current transfers
ΙΔΙΩΤΙΚΟΣ ΤΟΜΕΑΣ ⁽²⁾	163,7	169,4	193,2	205,6	214,9	223,4	234,6	PRIVATE SECTOR ⁽²⁾
Τρέχουσες Δαπάνες	159,6	163,7	188,6	200,4	207,6	216,1	226,9	Current Expenditure
(1) Ιατρικά και φαρμακευτικά προϊόντα	50,1	51,4	58,8	63,1	65,6	68,5	71,0	(1) Medical and pharmaceutical products
(2) Θεραπευτικές συσκευές και εξοπλισμός	6,7	6,9	8,0	8,4	8,8	9,1	9,6	(2) Therapeutic appliances and equipment
(3) Υπηρεσίες ιατρών, οδοντιάτρων και συναφών επαγγελματιών	75,9	77,9	89,8	95,5	99,3	103,7	109,8	(3) Physicians, dentists and other medical services
(4) Νοσοκομειακή περίθαλψη	18,9	19,4	23,5	24,8	25,0	25,8	27,1	(4) Hospital care
(5) Τέλη και ασφάλειες δυστυχημάτων	7,9	8,1	8,5	8,6	8,9	9,0	9,5	(5) Service charges on accidents
Κεφαλαιουχικές Δαπάνες	4,1	5,7	4,6	5,2	7,3	7,3	7,7	Capital Investments
ΣΥΝΟΛΟ ΔΑΠΑΝΩΝ	278,2	295,3	330,4	356,8	390,5	438,8	449,2	TOTAL EXPENDITURE
ΑΚΑΘΑΡΙΣΤΟ ΕΓΧΩΡΙΟ ΠΡΟΙΟΝ	4.862,8	5.214,2	5.679,0	6.103,6	6.370,3	6.836,2	7.292,1	GROSS DOMESTIC PRODUCT
ΠΟΣΟΣΤΟ ΔΑΠΑΝΩΝ ΥΓΕΙΑΣ ΣΤΟ Α.ΕΓΧ.Π. (%)	5,7	5,7	5,8	5,8	6,1	6,4	6,2	PERCENTAGE OF HEALTH EXPENDITURE ON G.D.P. (%)

Source: Cyprus Statistical Service (2005)

Table 2b: Bed occupancy rate

Νοσοκομείο	Ποσοστό καταλήψεως κλινών (%) Bed occupancy rate (%)			Μέσος όρος παραμονής (ημέρες) Average length of stay (days)			Hospital
	2002	2003	2004	2002	2003	2004 ¹	
Γενικό Λευκωσίας	81,3	80,4	95,5	8,1	8,0	8,7	Lefkosia General
Αρχ. Μακαρίου Γ' Λευκωσία	62,3	60,6	63,2	4,8	4,9	5,3	Arch. Makarios III Lefkosia
Γενικό Λάρνακας Μακάριος Γ'	71,2	72,8	76,6	5,0	4,9	5,2	Lamaka General Makarios III
Γενικό Λεμεσού	76,6	75,8	81,5	4,8	4,8	5,0	Lemesos General
Γενικό Πάφου	68,0	61,5	62,8	4,3	3,7	3,9	Pafos General
ΓΕΝΙΚΑ ΝΟΣΟΚΟΜΕΙΑ	73,5	72,8	79,9	5,6	5,5	5,9	GENERAL HOSPITALS
ΑΓΡΟΤΙΚΑ ΝΟΣΟΚΟΜΕΙΑ	31,7	37,7	30,1	5,4	6,0	5,2	RURAL HOSPITALS

Source: Cyprus Statistical Service (2004)

Table 3: Existence of history of specific health problem by sex and age category (male).

Πίνακας 3α (συν.). Υπαρξη ή Ιστορικό Συγκεκριμένων Προβλημάτων Υγείας κατά Φύλο και Κατηγορία Ηλικίας
 Table 3a (cont'd). Existence or History of Specific Health Problems by Sex and Age Category

Φύλο/Ηλικία Sex/Age	Ασθμα Asthma	Αλλεργία Allergy	Διαβήτης Diabetes	Καταράκτης Cataract	Υπέρταση Hypertension	Στηθάγγη/ Έμφραγμα Heart attack	Εγκεφαλικό επεισόδιο Stroke	Χρόνια Βρογχίτιδα Chronic Bronchitis	Αρθρο- πάθεια Arthritis	Οστεο- πόρωση Osteoporosis	Έλκος Ulcer	Καρκίνος όγκος Μήτρωμα Tumour	Ημικρανία/ Πονοκέφαλος Migraine/ Headaches	Χρόνια όγκος/ κατάθλιψη Chronic anxiety/ Depression
Ανδρες/Males	18.669	25.493	15.803	9.713	38.691	9.469	4.662	11.603	12.787	1.287	9.325	2.854	16.618	13.649
0-4	1.539	1.424	0	0	0	0	0	1.545	0	0	0	0	0	0
5-9	3.047	1.977	0	0	0	0	0	935	0	0	126	0	113	113
10-14	2.066	2.473	0	0	0	0	0	1.004	0	0	0	0	342	118
15-19	1.142	1.659	0	0	0	0	0	869	0	0	0	0	397	268
20-24	1.694	1.685	246	0	0	0	126	778	124	0	126	120	1.154	540
25-29	863	883	372	0	174	0	0	710	347	0	174	172	911	1.097
30-34	720	1.477	140	0	0	0	0	423	142	0	464	0	2.102	906
35-39	698	2.221	564	289	295	437	284	269	284	0	280	0	1.665	857
40-44	966	1.975	610	280	1.741	116	126	363	247	0	638	0	1.886	1.775
45-49	359	2.009	942	0	1.698	363	0	595	469	0	955	0	1.332	983
50-54	635	1.833	919	535	3.116	775	645	503	1.790	0	1.534	235	1.829	2.097
55-59	624	1.692	2.508	642	3.786	1.600	0	473	1.069	116	836	355	731	651
60-64	934	1.335	2.536	569	4.316	1.330	404	266	1.501	146	1.192	276	1.194	804
65-69	546	962	1.801	1.282	5.019	1.064	635	640	1.613	101	640	418	1.422	1.184
70-74	1.349	863	1.902	1.418	3.666	1.023	842	377	2.273	348	857	687	506	861
75-79	639	634	1.551	2.182	4.161	1.061	765	748	1.281	383	1.069	271	519	664
80-84	505	295	1.392	1.473	1.864	1.496	397	677	886	193	214	300	401	194
85+	323	97	322	943	855	204	437	428	761	0	218	0	106	536

Table 4: Existence of history of specific health problem by sex and age category (female).

Πίνακας 3α (συν.). Ύπαρξη ή Ιστορικό Συγκεκριμένων Προβλημάτων Υγείας κατά Φύλο και Κατηγορία Ηλικίας
 Table 3a (cont'd). Existence or History of Specific Health Problems by Sex and Age Category

Φύλο/Ηλικία Sex/Age	Άσθμα Asthma	Αλλεργία Allergy	Διαβήτης Diabetes	Καταράκτης Cataract	Υπέρταση Hypertension	Στηθάγγη/ Έμφραγμα Heart attack	Εγκεφαλικό επαισόδιο Stroke	Χρόνια Βρογχίτιδα Chronic Bronchitis	Αρθρο- πάθεια Arthritis	Οστεο- εόρωση Osteoporosis	Έλκος Ulcer	Κακοήθης όγκος Malignant Tumour	Ημικρανία/ Πονοκεφάλια Migraine/ Headaches	Χρόνια άγχος/ κατάθλιψη Chronic anxiety/ Depression
Γυναίκες/Females	19.080	37.089	12.640	13.106	39.533	3.832	2.217	13.177	35.146	22.936	11.597	6.258	44.614	27.491
0-4	887	592	0	0	0	0	0	590	0	0	0	0	0	0
5-9	1.797	1.094	0	0	0	0	0	1.002	0	0	0	0	0	0
10-14	1.028	1.238	111	0	6	6	0	346	0	0	0	105	232	123
15-19	567	2.151	0	121	0	0	0	434	108	0	229	0	228	478
20-24	1.449	1.108	163	0	0	0	6	324	0	0	153	0	1.894	1.126
25-29	830	2.153	0	0	0	178	0	328	178	0	356	157	2.173	2.058
30-34	1.182	2.300	0	0	138	124	0	757	648	0	255	245	3.214	1.303
35-39	640	3.175	273	0	511	136	136	647	511	130	353	388	3.456	1.746
40-44	1.033	3.137	135	127	540	125	6	268	1.591	377	782	250	5.511	2.008
45-49	2.136	4.749	775	0	2.496	127	127	932	2.069	392	1.395	529	4.757	2.954
50-54	1.085	3.337	1.263	140	3.214	0	0	809	3.028	1.214	946	924	4.775	2.193
55-59	2.080	2.999	1.196	358	3.988	587	231	596	3.967	3.452	1.183	1.085	3.662	2.815
60-64	586	2.181	1.353	476	5.765	112	113	1.261	4.491	2.663	1.149	447	3.652	2.608
65-69	1.260	1.861	2.050	2.067	6.092	628	508	1.000	4.468	4.427	894	509	3.669	2.434
70-74	946	2.413	2.054	2.888	6.786	793	404	1.862	5.275	4.057	1.562	535	2.890	2.714
75-79	1.067	1.798	1.420	2.988	4.716	124	471	1.083	4.707	3.457	727	600	2.781	2.082
80-84	349	675	936	2.086	3.268	227	227	817	1.977	1.985	1.282	356	1.305	708
85+	128	128	911	1.854	2.019	672	0	121	2.129	782	530	128	415	143

Table 5: Deaths by cause of death and sex 1997-2000

ΠΙΝΑΚΑΣ 64 (συνέχεια). ΘΑΝΑΤΟΙ ΚΑΤΑ ΑΙΤΙΑ ΘΑΝΑΤΟΥ¹ ΚΑΙ ΦΥΛΟ, 1997-2000

TABLE 64 (cont'd). DEATHS BY CAUSE OF DEATH¹ AND SEX, 1997-2000

Κώδικας Code	Αιτία θανάτου	1997			1998			1999			2000			Cause of death
		Σύν. Total	Ανρ. Males	Γυν. Fem.	Σύν. Total	Ανρ. Males	Γυν. Fem.	Σύν. Total	Ανρ. Males	Γυν. Fem.	Σύν. Total	Ανρ. Males	Γυν. Fem.	
1023	Τρυπανοσομίαση	0	0	0	0	0	0	0	0	0	0	0	0	Trypanosomiasis
1034	Σχιστοδομίαση	1	1	0	0	0	0	0	0	0	0	0	0	Schistosomiasis
1025	Άλλες λοιμώξεις και παρασιτικές ασθένειες	0	0	0	0	0	0	9	4	5	1	0	1	Remainder of certain infectious and parasitic diseases
1026	Νεοπλασμάτα	417	232	185	450	263	187	447	242	205	411	256	160	Neoplasms
1027	Κακοήθες νεόπλασμα χείλους, στόματος και φάρυγγα	0	0	0	0	0	0	4	4	0	6	5	1	Malignant neoplasm of lip, oral cavity and pharynx
1028	Κακοήθες νεόπλασμα οισοφάγου	3	2	1	3	2	1	3	1	2	2	2	0	Malignant neoplasm of oesophagus
1029	Κακοήθες νεόπλασμα στομάχου	17	11	6	18	11	7	16	10	6	10	6	4	Malignant neoplasm of stomach
1030	Κακοήθες νεόπλασμα κόλου και πρωκτού	33	18	15	30	15	15	37	18	19	49	31	18	Malignant neoplasm of colon, rectum and anus
1031	Κακοήθες νεόπλασμα ήπατος και ενδοηπατικών χοληφόρων πόρων	18	11	7	17	9	8	25	15	10	16	10	6	Malignant neoplasm of liver and intrahepatic bile ducts
1032	Κακοήθες νεόπλασμα παγκρέατος	20	13	7	23	11	12	18	11	7	21	18	3	Malignant neoplasm of pancreas
1023	Κακοήθες νεόπλασμα λάρυγγα	0	0	0	0	0	0	3	3	0	0	0	0	Malignant neoplasm of larynx
1034	Κακοήθες νεόπλασμα τραχείας, βρόγχου και πνεύμονα	63	52	11	81	63	16	69	49	20	55	31	4	Malignant neoplasm of trachea, bronchus and lung
1035	Κακοήθες νεόπλασμα δέρματος	1	1	0	0	0	0	8	5	3	2	2	0	Malignant melanomas of skin
1036	Κακοήθες νεόπλασμα μαστού	38	0	38	36	0	36	39	0	39	28	2	26	Malignant neoplasm of breast
1037	Κακοήθες νεόπλασμα τραχήλου μήτρας	13	-	13	5	..	5	4	..	4	4	-	4	Malignant neoplasm of cervix uteri
1038	Κακοήθες νεόπλασμα μη καθορισμένων μερών της μήτρας	0	..	0	0	..	0	2	..	2	2	-	2	Malignant neoplasm of other and unspecified parts of uterus
1039	Κακοήθες νεόπλασμα ωοθηκών	11	..	11	12	..	12	10	..	10	9	-	9	Malignant neoplasm of ovary
1040	Κακοήθες νεόπλασμα προστάτη	26	26	..	19	19	..	34	34	..	36	36	..	Malignant neoplasm of prostate
1041	Κακοήθες νεόπλασμα κύστης	4	2	2	2	2	0	8	4	4	7	5	2	Malignant neoplasm of bladder
1042	Κακοήθες νεόπλασμα εγκεφάλου και άλλων τμημάτων του κεντρικού νευρικού συστήματος	0	0	0	3	3	0	37	20	17	24	9	15	Malignant neoplasm of meninges, brain and other parts of central nervous system

(συνέχεια-contin'd)

Source: Cyprus Statistical Service (2004)

Table 6: Patients discharged General Hospitals by disease, sex and length of stay, 2003

ΠΙΝΑΚΑΣ 11 (συνέχεια). ΑΠΟΛΥΘΕΝΤΕΣ ΑΣΘΕΝΕΙΣ ΑΠΟ ΤΑ ΓΕΝΙΚΑ ΝΟΣΟΚΟΜΕΙΑ ΚΑΤΑ ΑΣΘΕΝΕΙΑ, ΦΥΛΟ ΚΑΙ ΔΙΑΡΚΕΙΑ ΠΑΡΑΜΟΝΗΣ, 2003
TABLE 11 (cont'd). PATIENTS DISCHARGED FROM GENERAL HOSPITALS BY DISEASE, SEX AND LENGTH OF STAY, 2003

ICD-10		Απολυθέντες ασθενείς Patients discharged			Ημέρες νοσηλείας Hospital days		Disease and sex		
Κατηγορία	Κατάλογος τριψήφων κατηγοριών	Ασθένεια και φύλο	Όλοι	Ζωντανοί	Νεκροί	Μέσος όρος παραμονής Average length of stay			
Category	List of three-character categories		Total	Alive	Dead			Total	
B35-B49	Μυκητιάσεις	Όλοι	3	3	0	10	3,3	Mycoses Total Males Females	
		Ανδρες	1	1	0	5	5,0		
		Γυναίκες	2	2	0	5	2,5		
B50-B54	Ελονοσία	Όλοι	2	2	0	6	3,0	Malaria Total Males Females	
		Ανδρες	2	2	0	6	3,0		
		Γυναίκες	0	0	0	0	0,0		
B55	Λεισημανίαση	Όλοι	1	1	0	4	4,0	Leishmaniasis Total Males Females	
		Ανδρες	1	1	0	4	4,0		
		Γυναίκες	0	0	0	0	0,0		
B67	Εχινόκοκκος	Όλοι	6	6	0	78	13,0	Echinococcosis Total Males Females	
		Ανδρες	2	2	0	7	3,5		
		Γυναίκες	4	4	0	71	17,8		
A65-A67, A69-A70, A74,A77- A79,B38-B64, B85-B89,B94,	Άλλες λοιμώδεις και παρασιτικές ασθένειες	Όλοι	27	27	0	133	4,9	Other infectious and parasitic diseases Total Males Females	
		Ανδρες	19	19	0	95	5,0		
		Γυναίκες	8	8	0	38	4,8		
II	C00-D48	Νεοπλασμάτα	Όλοι	3.574	3.401	173	25.996	7,3	Neoplasms Total Males Females
			Ανδρες	1.889	1.789	100	13.177	7,0	
			Γυναίκες	1.685	1.612	73	12.819	7,6	

Source: Cyprus Statistical Services (2004)

Table 7: Patients discharged from Rural Hospitals by disease, age and length of stay, 2003

ΠΙΝΑΚΑΣ 12 (συνέχεια). ΑΠΟΛΥΘΕΝΤΕΣ ΑΣΘΕΝΕΙΣ ΑΠΟ ΤΑ ΑΓΡΟΤΙΚΑ ΝΟΣΟΚΟΜΕΙΑ ΚΑΤΑ ΑΣΘΕΝΕΙΑ, ΦΥΛΟ ΚΑΙ ΔΙΑΡΚΕΙΑ ΠΑΡΑΜΟΝΗΣ, 2003

TABLE 12 (cont'd). PATIENTS DISCHARGED FROM RURAL HOSPITALS BY DISEASE, SEX AND LENGTH OF STAY, 2003

ICD-10	Κατηγορία	Κατάλογος κατηγοριών ασθενών και φύλο	Απολυθέντες ασθενείς			Ημέρες νοσηλείας		Disease and sex	
			Ολικό	Ζωντανοί	Νεκροί	Ολικό	Μέσος όρος παραμονής		
Category	List of three-character categories		Total	Alive	Dead	Total	Average length of stay		
A75	Εξονηγματικός τίφος	Ολικό	2	2	0	7	3,5	Typhus fever	
		Ανδρες	1	1	0	4	4,0		Total
		Γυναίκες	1	1	0	3	0,0		Males
B16	Οξεία ηπατίτιδα Β	Ολικό	1	1	0	1	1,0	Acute hepatitis B	
		Ανδρες	0	0	0	0	0,0		Total
		Γυναίκες	1	1	0	1	1,0		Males
B15, B17-B19	Άλλες ιογενείς ηπατίτιδες	Ολικό	1	1	0	23	23,0	Other viral hepatitis	
		Ανδρες	0	0	0	0	0,0		Total
		Γυναίκες	1	1	0	23	23,0		Males
A81, A87, A89, B03-B04, B07-B09, B23, B27-B34	Άλλες ιογενείς ασθένειες	Ολικό	13	13	0	50	3,8	Other viral diseases	
		Ανδρες	9	9	0	38	4,2		Total
		Γυναίκες	4	4	0	12	3,0		Males
II	C00-D48	Νεοπλασμάτα	Ολικό	58	52	6	293	5,1	Neoplasms
		Ανδρες	44	40	4	204	4,6	Total	
		Γυναίκες	14	12	2	89	6,4	Males	
C16	Κακοήθες νεόπλασμα του στομάχου	Ολικό	3	3	0	16	5,3	Malignant neoplasm of Stomach	
		Ανδρες	3	3	0	16	5,3		Total
		Γυναίκες	0	0	0	0	0,0		Males
C18	Κακοήθες νεόπλασμα του κόλου	Ολικό	4	4	0	16	4,0	Malignant neoplasm of colon	
		Ανδρες	3	3	0	11	3,7		Total
		Γυναίκες	1	1	0	5	5,0		Males

Source: Cyprus Statistical Services (2004)

Table 8: Expenditure on health services 1998-2003 in Cyprus

SUMMARY TABLE V. EXPENDITURE ON HEALTH SERVICES, 1998-2003

<i>£ εκατ.</i>							<i>£ mn</i>
Ανάλυση	1998	1999	2000	2001	2002	2003	Analysis
ΔΗΜΟΣΙΟΣ ΤΟΜΕΑΣ	114,5	125,9	137,2	151,2	175,6	215,4	PUBLIC SECTOR
(1) Ακαθάριστες επενδύσεις	6,4	9,5	10,8	11,1	17,8	24,2	(1) Gross capital formation
(2) Αμοιβές υπαλλήλων	69,7	73,7	79,2	85,2	90,8	106,2	(2) Compensation of employees
(3) Κοινωνικές εισφορές και παροχές	9,8	9,8	11,9	12,6	15,5	16,6	(3) Social benefits
(4) Ενδιάμεση Ανάλωση	26,8	30,3	32,2	37	44,8	62,5	(4) Intermediate consumption
(5) Λοιπές τρέχουσες μεταβιβάσεις	1,8	2,6	3,1	5,3	6,7	5,9	(5) Other current transfers
ΙΔΙΩΤΙΚΟΣ ΤΟΜΕΑΣ	144,4	159,6	180,1	191,3	199,9	211,1	PRIVATE SECTOR
Τρέχουσες Δαπάνες	140,3	153,9	175,5	186,1	192,6	203,8	Current Expenditure
(1) Ιατρικά και φαρμακευτικά προϊόντα	33,3	38,8	57,1	66,8	65,4	66,3	(1) Medical and pharmaceutical products
(2) Θεραπευτικές συσκευές και εξοπλισμός	6,2	8,1	8,4	4,9	7,2	7,6	(2) Therapeutic appliances and equipment
(3) Υπηρεσίες ιατρών, οδοντιάτρων και συναφών επαγγελματιών	72,0	76,7	75,5	81,2	84,4	91,8	(3) Physicians, dentists and other medical services
(4) Νοσοκομειακή περίθαλψη	26,1	27,3	29,8	28,5	29,4	31,1	(4) Hospital care
(5) Τέλη και ασφάλειες δυστυχημάτων	2,7	3,0	4,7	4,7	6,2	7,0	(5) Service charges on accidents
Κεφαλαιουχικές Δαπάνες	4,1	5,7	4,6	5,2	7,3	7,3	Capital Investments
ΣΥΝΟΛΟ ΔΑΠΑΝΩΝ	258,9	285,5	317,3	342,5	375,5	426,5	TOTAL EXPENDITURE
ΑΚΑΘΑΡΙΣΤΟ ΕΓΧΩΡΙΟ ΠΡΟΙΟΝ	4.862,8	5.214,2	5.679,0	6.103,6	6.370,3	6.801,7	GROSS DOMESTIC PRODUCT
ΠΟΣΟΣΤΟ ΔΑΠΑΝΩΝ ΥΓΕΙΑΣ ΣΤΟ Α.ΕΓΧ.Π. %	5,3	5,5	5,6	5,6	5,9	6,3	PERCENTAGE OF HEALTH EXPENDITURE ON G.D.P. %

Source: Cyprus Statistical Services (2003)

Table 9. Structural explication for the main theme “Receiving care in easily accessible cancer care services”

Meaning Units (Condensed)	Sub – themes	Themes	Main Theme
<p>A. “It is not easy for me coming here [cancer care department] to take my treatment which means that I have to be admitted about every two weeks or earlier sometimes when I am not well. You see I am not from this town [Nicosia], and I have to travel from Paphos to come here which is expensive. The kind of treatment I need or any other kinds of cancer care are not provided in Paphos General Hospital. There have been times that I preferred to go to the General Hospital and from there transferred to a specialised centre. It is not fair, for us, I mean after all we do pay the same taxes as with anyone else, therefore why do people from Nicosia have a privileged cancer care, are we second category civilians? (M-68, PI-15)</p> <p>B. “Access to care is problematic in my point view. For us, the people living in rural and urban areas it is very difficult to get any treatment for cancer when we get sick, my fear is that will not be there to get treated. The closest hospital that provides such care is around 200 kilometres from here and when you do not have a car this can be a huge problem, and I do not only</p>	<p>A.1. Patients with cancer often have to travel great distances just to get their basic treatment.</p> <p>A.2. Lack of equity in access</p> <p>A.3. Centralisation of services is impacting access to care.</p> <p>A.4. Patients’ treatment sometimes postponed due to inability of the services to meet the demand or due to the inability to be present at the specialised centre.</p> <p>B.1. Reliance on family members especially their children to take them for the treatments.</p> <p>B.2. Psychological distress of the patient and the family. Some patients blame themselves for problems arising in the family as a result of the frequent treatments and their need for support</p>	<p>A. Geographical inequalities for availability and access to cancer care services</p> <p>B. Family burden from taking the patient for his/her treatment and assuming responsibility for other aspects of the care</p>	<p>Receiving care in easily accessible cancer care services</p>

<p>mean a financial problem. Very often I ask my children to take me there but admissions and other arrangements need to be made in the morning and this means that they have to take time-off from work and this can be very stressful for them, it is ok in the first couple of times but after that their bosses begin not to be so cooperative. At the same time they also have to leave their own families behind, and this is heavy on my consciousness [specifically referring to young children]" (M-65, PI-5) "Something needs to be done. I think that my family had enough, I do not know if they can take it any more. They pay my taxi to come here; they hardly see their children when I am admitted and their husbands are not so understandings anymore. I do not blame them" (F-58, PI-23).</p> <p>C. "Coming here [in the cancer care department] used to be easier than before. Now that I am so dependant on my family I rely on them to take me to the hospital, among the other things they do for me. We live so far from here that every time I have to be admitted I spend most of the time alone [meaning without her family], and the visitation policy makes things no easier, I am not complaining of the care or</p>	<p>and travelling (assuming patient's care)</p> <p>B.3. Work problems arise for the members of the family.</p> <p>C.1.Treatment for certain patients means that they have to spend significant time away from their families.</p> <p>C.2.Poor access to services and visiting policies means that the family spends limited time with the patient.</p>	<p>C. Family's presence, which is recognised by the patient as an important factor during hospitalisation, is negatively influenced by poor access.</p>	
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<p>anything, but it makes me feel safer and relaxed when they are around, they have the way to keep my spirit up no matter how bad things are” (F-44, PI-13). “Quality nursing care is a difficult task for the nurses, especially with patients with cancer. Unfortunately, nurses sometimes do not take advantage of the facilitating role of the family in achieving this goal. The family can act as a mediator between the patient and the nurse, improving patient’s adherence to treatment and his/her cooperation with the nursing staff [...] (FG with PA)</p> <p>D. “I have cancer in my bones for almost two years now, this has made me a handicapped person. I need a wheelchair to move and to come here is only possible with the help of my family. There was no planning so that other means of public transport could be offered by the government to the patients. Most care is given in Nicosia and we are ‘forced’ to come here [...] and why Nicosia in the first place and not Limassol instead which is at a junction of all cities? They opened the cancer department in Limassol but the range of care provided is limited....I get the feeling that it something that was done just for the people’s eyes [to relieve the</p>	<p>D.1.The Ministry ignores the essence of the problems of the patients and their families.</p> <p>D.2.Poor planning negatively influences the availability and access to resources and services.</p> <p>D.3. Decisions are politically driven instead of patient driven.</p>	<p>D. Political decisions lack planning and create inequalities.</p>	
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<p>pressure off the Ministry of Health]” (F-57, PI-1) “The health sector in Cyprus is suffering. I do not know about other groups of patients but for us the patients with cancer things are getting worse by the year. There are not sufficient services available to meet the increased demands. Instead of doing things to solve the problem, last year [2005] the minister [health] closed the oncology ward in the Nicosia General Hospital. Is this a reasonable action by the Ministry? (M-66, PI-24) “Quality nursing care can be and should be defined in terms of the quality of the services provided, however before one evaluates this, one should first of all evaluate whether these are available to the patients all over Cyprus and can be easily accessible by them. Unfortunately, the policy of the Ministry and hence the government is to provide cost-containment services which create inequalities in relation to who is able to receive cancer care (PA-FG)</p> <p>E. “What quality are you referring to? That the nurses and physicians do not have medicines to give us? That we have to wait for hours and sometimes even days just to get a bed in order to be treated? That most of us have to travel away from our cities to get treated?” (M-21, PI-3, FG-1)</p>	<p>E.1. Patient argues that there can not be quality of care without the provision and access of care.</p> <p>E.2. Stress the lack of resources, poor availability and access to cancer care services.</p>	<p>E. “Quality nursing care” is interpreted as being able to access the cancer services which are widely available.</p>	
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Table 10. Structural explication for the nurses' response to main theme "Receiving care in easily accessible cancer care services"

Meaning Units (Condensed)	Sub - themes	Themes	Main Theme
<p>A. "I do not agree with the patients' expressed views on this matter. I can hardly see the connection between the two [meaning quality nursing care and access]. Nursing care is nursing care and its quality begins as soon as the patient is admitted in the ward and the nurse begins to care for the patient. That is, and should be, in my opinion the starting point of quality...and quality should be defined and assessed from this point onwards" (M-31, SNI-6).</p> <p>B. "I think that access and availability as the patients referred to it involve issues beyond the control of the nurse, and the nursing profession in general. And if you can not control these issues how is it possible to be liable for them or how can you be able to change them in order to improve access and availability? It is a matter simply out of our league. However, if the nurse through her constant contact with the patient identifies such problems or the patient himself expresses such problems, then it is my belief that she must take these concerns and problems to the management committee of the hospital so that actions can be taken at an</p>	<p>A.1. Disagreement with the patients views</p> <p>A.2. Nursing quality begins when the patient is cared for</p> <p>B.1. Nursing can not have power over access and availability factors</p> <p>B.2. Recognition of these issues through patient contact and informing administration</p> <p>B.3. Access and availability are important for quality of care but not for quality nursing care</p> <p>B.4. Difficult to differentiate between "quality care" and "quality nursing care"</p>	<p>A. Quality is achieved through nurses caring.</p> <p>B. Beyond the scope of nursing</p>	<p>Availability and access to services are not related to the concept of "quality nursing care"</p>

administrative level towards the solution of these problems. From this point of view I would say that nursing has the duty to help the patient in the way I have described to you" (F-45, WMI-14) "Access and availability are important elements of the quality of care, it is my guess that they speak about quality in a more holistic way...I mean that the actions of all health care professionals involved in the care of the patient are included...on the other hand nursing is a separate science and its quality should refer only to those actions made by the nurse as part of the patient's caring. Of course I am not only a provider but also a user of the services therefore I can get into the minds of the patients even for just a bit and see what they were thinking when they made these claims. The main reason I think is often their difficulty to separate where nursing care begins and where nurses can influence something with their work, we are not expecting the patients to know such details however, it is up to us to inform them" (F-28, SNI-5)

Table 11. Structural explication for main theme “Being cared for by nurses who effectively communicate with them and their families and provide emotional support

Meaning Units (Condensed)	Sub – themes	Themes	Main Theme
<p>A. “Quality nursing care is...includes many different things but for me being able to communicate with my carers is perhaps the most important. Otherwise is like being treated by “mute” carers. To consider nursing care as quality then communication needs to be healthy, this is my measure against which I value nursing care. However, trying to communicate with the nurses or the physicians in this ward is not the easiest thing. Everything in this ward are characterised by a level of ...mysticism¹³¹. Many times during my treatment I had questions regarding my disease, my medications and my care in general, however, when I tried to clarify these the answer I got was “not now I am busy”, or “I can not explain this in simple words so that you can understand” and even when they find some time for us they speak in a “foreign” language that we are unable to understand [...]” (F-57, P-1).</p> <p>B. “Yes there are problems with communicating with certain nurses; however I do not want to make any</p>	<p>A.1. Patients referred to quality nursing care in terms of being able to have a healthy communication with their nurses.</p> <p>A.2. Bad communication is due to the nurses’ belief that most patients are unable to understand technical terms.</p> <p>A.3. Nurses according to the patients seem to “hide” behind the ward routine and the lack of time to justify their behaviour of poor or ineffective communication.</p> <p>B.1. Nurses rarely listen to the patients and this restrains good communication.</p>	<p>A. Communication although a constituent of quality nursing care remains hermetic</p> <p>B. Communication tends to be one-sided.</p>	<p>Quality nursing</p>

¹³¹ In Greek – *Μυστικοπάθεια, Μυστικότητα*

<p>generalisations because not all the nurses are the same and some of the nurses have been lovely so far. I believe that bad communication is quite often when attempting to move beyond what I call the 'routine communication agenda'. What I mean is that nurses rarely listen to us...they can <i>hear</i> us speaking to them but they do not necessarily <i>listen</i> to us, thus the communication tends to be one-sided" (F-58, P1-23)</p> <p>C. "[...] The nursing staff is really wonderful and many times I found myself in situations where they knew what I was feeling at those particular moments without even saying anything. However, what I appreciate the most is that when I am "down" or feeling "blue" the nurses can pick up these silent signals and act upon it, they do their best to engage me into a conversation or do something else just to take my mind away of my illness and the worries that come with it. They can even involve my family in this attempt, I do not know how they can do it but what I know is that it emotionally comforts me [...] That is why I would say that good communication is [...] an important element of the quality nursing care" (M-57, PI-14, FG-1).</p> <p>D. "Communicating means the ability to</p>	<p>B.2.Sometimes nurses intentionally avoid getting into a deeper communication with their patients. They seem to have adopted a typical (superficial) communication method which rarely exceed.</p> <p>C.1.Verbal and Non-verbal communication skills are valued by patients and the family.</p> <p>C.2.Identifying voiced and unvoiced patients' needs and implementation of strategies in order to help the patients.</p> <p>D.1.Communication allows the</p>	<p>C. Good communication skills are valued by the patient and the family as a means to improve care.</p> <p>D. Through</p>	<p>care is about being able to communicate with the nurse about health and personal issues</p>
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<p>reach out for the other [...] Speaking to and being understood, without this essential component [...] nursing care can not be complete or of high quality. Nurses need to communicate with the patient and know him/her, know about him/her and care for him/her specifically and not based on standardised 'routine' ways. It is equally important that the nurses establish good communication with the patient's family as well, because family may also need support and can also be an important source of support for patients with cancer and the nurse should work on this to the patient's benefit. If the nurse does not have the abilities to unveil through communication the patient's feelings, particularities, concerns and silent or unvoiced needs then he/she can only care for the patient in a "raw" and "cold" manner, which of courses will reflect on its quality [...] (FG with PA).</p>	<p>nurse to know the patient's world of experiences and feelings.</p> <p>D.2. Knowing the patient allows the nurse to care for the patient based on his/her individualised needs.</p> <p>D.3. Establishing good communication with the family.</p>	<p>communication nurses can better understand the patient and the family.</p>	
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Table 12. Structural explication for main theme “Being empowered by nurses through information giving”

Meaning Units (Condensed)	Sub – themes	Themes	Main Theme
<p>A. “Spending 24 hours a day around nurses allows me to have a ‘special’ relationship and a better communication with them. I can trust them and I expect of them to inform me and be honest for anything regarding my health. [...] Quality of care is partly to keep us informed and it’s their job for doing so. The physician is around only for a few minutes during the day and almost never at night and in order for nurses to be there for us they must be in a position to provide such information” (F-58, PI-11, FG-1) “Quality is achieved when the patient is informed and there many reasons why I think this. For example an informed patient is more likely to share decisions responsibilities and also be an active participant in his/her own care. With the provision of information the patient is empowered and he/she can influence decision making [...]”(FG with Patients Advocates)</p> <p>B. “I can not be sure if the nurses do not want or they are allowed to provide such information [disease related], perhaps the hospital or even the physicians prohibit them for doing so, [...] Usually I get the sense that the nurses definitely know more than they tell us [...]” (M-21, PI-3, FG-1).</p>	<p>A.1. Quality nursing care is seen as informing the patient.</p> <p>A.2. Proximity and constant contact with the nurse creates a trusting environment that promotes better communication.</p> <p>A.3. Participation in shared decision-making through information giving.</p> <p>B.1. The hospital disables nurses from adequately informing patients.</p> <p>B.2. Information provides physicians with power over the patient.</p>	<p>A. Proximity and trust enables information sharing.</p> <p>B. Organisational culture and lack of policy.</p>	<p>Empowering patients through information giving</p>

<p>C. “But, er, some members of the staff [nurses and physicians] do not take you into their confidence and hardly give you any meaningful information or when they give it to you, you are lucky if you understand a few words. Either they think you are stupid or else not interested” (F-21, PI-6, FG-2) “Information is not enough for us. Yes they give us some information, but in my opinion it’s only on a need-to know basis. As a Greek-Cypriot is in my culture to want to crosscheck¹³² the information provided to me taking nothing for granted, and the nurse is the most reliable and accessible source to do this” (M-65, PI-22).</p>	<p>C.1. Assumption that the patients are not interested or able to understand disease related information.</p> <p>C.2. Tailored information to suit patient’s educational background, cultural orientation, and general level of comprehension.</p> <p>C.3. Patients intentionally request information from the physicians and the nurses so that they can have a clearer and “truer” picture of their situation (health status).</p>	<p>C. Nurses beliefs and attitudes.</p>
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¹³² Crosscheck – In Greek – Διασταυρώνω

Table 13. Structural explication for nurses' response to main theme "Being cared for by nurses who effectively communicate with them and their families and provide emotional support and being empowered by nurses through information giving"

Meaning Units (Condensed)	Sub - themes	Themes	Main Theme
<p>A. "Communicating with the patients has not been the easiest task in my nursing career [...]. I do not speak for all my colleagues but I strongly believe that we pretty much sitting in the same spot. You see the problem is that [...] we have not received any formal or any other training on how to develop our communication skills, therefore I solely rely on my experience and what I have learnt from others, unfortunately I can not claim that I am always engaging in a good communication with my patients or even their families...the problems are there andI perfectly understand the patients when they complain about bad communication. However, bare in mind that what the patients perceive as bad communication might be a weakness on either side to receive or send the intended message whether this is some disease related information or simply a feeling" (M-35, WMI-12)</p> <p>B. "[...] There are times that providing adequate information to patients can be psychologically harmful for them. What</p>	<p>A.1.Lack of formal training for developing communication skills during or after their nursing education.</p> <p>A.2.In Cyprus the nursing education curriculum does not comprise training on communication skills.</p> <p>A.3.Nurses are struggling to attain and maintain good communication with the patients.</p> <p>B.1. Nurses hold such beliefs that only selective information should be given to patients.</p>	<p>A. Lack of formal communication skills education which is considered by nurses a burdensome aspect of the care.</p> <p>B. Nurses' beliefs on informing the patients.</p>	<p>The meaning of quality nursing care is related to effectively communicating and informing the patients on every aspect of their care.</p>

<p>you do not know will not hurt you [...] and not knowing that you suffer from cancer can sometimes be beneficial for the patients and help them to get better if they think they suffer from something else, not to bring up that many times information can be misinterpreted. Cancer in Cyprus is a feared disease, often dealt with as curse, punishment, and sin that leads to death. Superstitions on this matter are difficult to change [...] The families in most cases prefer us not to tell or give any specific information to their patients, believing this way that they are protecting them, this is more frequent, absolute I would say, when the patient is a child or an elderly person" (F-31, SNI-7) "Many times in the past I tried to inform patients and their relatives on their care and treatment...however, what I had to face was negativity from some patients and relatives to receive such information. It is so burdening choosing what to say or what not to say and when is the best time to do this...I have given it up now... most patients prefer to "stay in the dark" and let me care for them as I think is best...so I go along with this, which makes my job a lot easier (M-37, SNI-10)</p> <p>C. "The patients comments make me feel as if we are the accused and we have to</p>	<p>B.2.Information may not be understood in the correct way or it is perceived that they do not want to receive any information about their disease.</p> <p>B.3.The collective character of the Greek-Cypriot family operates as a "protective" and "filtering" mechanism.</p> <p>C.1.The lack of related policy on informing the patients makes the</p>	<p>C.Policy restraints to informing the patients.</p>	
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<p>provide excuses for the bad communication and the poor provision of information. When the patients complain of poor provision of information related to their disease, diagnostic tests, lab results or any other aspects of the care their complains should be directed to the Ministry [of Health]. They make policy and have control over the hospitals. The current policy or protocols do not allow as giving any specific or detailed information to the patient, something that only the physician is allowed to do. Physicians are strict about this aspect of the care and therefore we have to stick to the rules, even if sometimes we do bend them to the benefit of the patient. However, we do refer the patients to the physicians when they need any disease related information. Protocols should be adopted on how and what to inform the patients about. Let's not forget that we are not physicians and therefore some treatment options and their effects might be unfamiliar to us" (M-50, WMI-13)</p>	<p>job of the nurses difficult.</p> <p>C.2. There is need for protocols in clinical practice.</p>		
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Table 14: Structural explication for main theme “Being cared for by clinically competent nurses”

Meaning Units (Condensed)	Sub - themes	Themes	Main Theme
<p>A. “For me “quality nursing care” is by definition a competent nurse caring for you. A competent nurse is the one that knows what she is doing. Most of the nurses in this ward, give you a sense that their knowledgeable and skilful when they care for you...that is taking your vital signs, checking the iv drip, giving your medication preparing you for the many diagnostic tests that we have to go through. Being treaded in here several times enabled me to pick up on the things that really matter for me.... I remember when I had to do a dangerous procedure...the nurses were so well-informed and understanding...They felt about me...were there and knew what to do to help me built my confidence level...however this did not happen from the beginning of my care...it took time... This is what the nurses do all the time” (F-21, P1-6, FC-2).</p> <p>B. “Capable nurses are those who have the professional knowledge to offer high quality nursing care. They have the experience to do the ‘right’ things whenever and wherever. The ‘right’ things are starting the IVs or drawing blood without having to</p>	<p>A.1. Quality nursing care and nurse’s competency are linked.</p> <p>A.2. Competent nurse is the one that “knows what she is doing”.</p> <p>A.3. Successfully performing the nursing procedures.</p> <p>B.1. Meeting patient’s physical needs.</p> <p>B.2. Carrying out nursing clinical procedures and helping the patient with daily living</p>	<p>A. Caring by skilled and knowledgeable nurses</p> <p>B. Competent nurses address patient’s physical needs through professional knowledge and technical competence.</p>	<p>Being cared for by clinically competent nurses</p>

<p>puncture us ten times, observing the chemotherapy or dressing the wound ...Important are not just these technical staff...helping you out of the bed, taking you to the shower, bringing you that extra blanket when you are cold are all of equal importance [...] sometimes talking to them I do not mean only about treatments, diseases but rather more personally can be all that I need [...]" (F-42, P1-16, FG-1). "Coming here makes me feel relaxed and safe having the nurses caring for me... Doing all those things to deal with my problem...I know that they will be there when I need something, or have a question about my treatment, or medication...How not to feel safe in this sort of environment? I am only sad for those cases when the nurses fell short of my expectations, and these cases are countable on the fingers of my hand" (M-62, P1-7).</p> <p>C. "Competent nurses are the key to quality nursing care. When they have the relevant knowledge and technical skills can efficiently meet all the planned or unplanned needs of the patients. However, a common problem in Cyprus is having general nurses treating patients with cancer, most of the times without any additional training or experience. This may lead [...] to patients experiencing several problems, like unsuccessful needs assessment and</p>	<p>activities.</p> <p>B.3. Clinically competent nurses promote a feeling of safety among patients.</p> <p>C.1. Quality nursing care depends of competent nurses delivering the care.</p> <p>C.2. Limited opportunities for gaining specialty in cancer care in Cyprus.</p> <p>C.3. Non-specialised nurses may be ill-equipped to care for the patient with cancer.</p>	<p>C. Limited availability of cancer specialty nurses.</p>	
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<p>poor satisfaction or inability on behalf of the nurse to provide the patient with specific information on cancer and cancer treatments. The problem is that at the time such training is not provided either by the state or any other private organisations. Sometimes nurses working with individuals with cancer experience such burden and burn-out that forces them to leave their jobs or ask for transfer to other wards. Those nurses that have specialty in cancer care have gained their qualification privately [...] paying for their additional education overseas, due to the limited opportunities for scholarships or grants [...]”(FG with PA).</p>			
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Table 15: Structural explication for nurses' response to main theme "Being cared for by clinically competent nurses"

Meaning Units (Condensed)	Sub-themes	Themes	Main Theme
<p>A. "I could not say it better myself. The patients and their advocates raised an important issue here [caring for people with cancer by specialised staff]. I am a general nurse and sometimes I find my training lacking to help me deal with a difficult situation. I have only been working in this cancer department for a year and I must admit that it is not easy to emotional or psycho-social aspects of the care...Deal with the patients or their families, <i>feels like walking through a minefield</i>¹³³....Getting the technical skills was necessary of course but not so difficult, getting to know the patients, supporting them emotionally, learning how they behave and how you should react, satisfying their social needs, and how to promote trust however, proved to be the most difficult aspects of my work...I am still working on these, but is hard without support [meaning from the hospital]....Perhaps if I can achieve this then I could say that I am offering quality nursing care to my patients" (M-3I, SNI-6)</p> <p>B. "[...] It is natural that a clinically</p>	<p>A.1.Clinically competent nurses are a prerequisite for quality nursing care.</p> <p>A.2.Nurses experientially become skilled at technical competencies however; it is more complicated to know the patient, emotionally support him/her, and offer reassurance.</p> <p>A.3.In their efforts to deliver clinically competent nursing care, nurses do not have the necessary support.</p> <p>B.1.Caring by clinically</p>	<p>A. Clinical competency includes more qualities than technical skills.</p> <p>B. Competency promotes</p>	<p>Quality nursing care as clinically competency which includes technical and interpersonal skills and knowledge.</p>

¹³³ A Metaphor often used to describe a difficult and tricky situation where the person does not know what to do and he/she must be extra cautious

<p>competent nurse can promote the sense of safety among our patients. Everything we do and how we do it and how we behave gives them the feeling that we are doing our job as best as we can and most importantly in the appropriate way. This makes them feel safe [...]. Trusting us on the other hand is a more difficult task to achieve which does not happen overnight but only after several encounters with the patient. Through these encounters the patients “submit” us in little “tests” that evaluate whether you can be trusted or not. We are required to develop good communication and interpersonal skills through training and experience...The patient wants to see a nurse that has a real interest in him/her, has someone to talk to other than his/her family, to offer support....That’s when a trusting relationship is developed which positively influences the quality of the care. A clinically competent nurse is able to meet the voiced and unvoiced needs of the patient in a holistic way which is what the patients hope for and expect from us” (F-54, WMI-20).</p> <p>C. “Our Ministry and the hospital did not do what was necessary to staff the cancer care departments with specialised nurses who are also trained to address the psycho-social and spiritual needs of the patients. Training in the School of Nursing as well as continued education programs should expand on these</p>	<p>competent nurses helps patients to feel in safe hands when cared for.</p> <p>B.2.Gaining the patient’s trust requires certain qualities from the nurse.</p> <p>B.3.Clinically competent nurses can care for the patient holistically.</p> <p>C.1.Training from nursing school and continues education programs does not promote clinically competency.</p> <p>C.2. A clinical competent</p>	<p>the feeling of safety among patients.</p> <p>C. Barriers to caring by clinically competent nurse.</p>	
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<p>aspects of the care and not cover them superficially. Despite this lack of training for most nurses, I strongly believe that they still manage to offer quality nursing care to patients. When their training is not sufficient to support the patient, then the nurse should be able to engage other professionals in the care (i.e. priest, psychologist). Clinical competency is not only about the qualities that you have but it is also the ability to collaborate and coordinate the team in the best interest of the patient; and doing this you need the necessary training” (M-55, WMI-17).</p>	<p>nurse should also receive training for the development of coordination and collaboration abilities.</p>		
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Table 16: Structural explication for the main theme “Nurses addressing patients’ religious and spiritual needs”

Meaning Units (Condensed)	Sub – themes	Themes	Main Theme
<p>A. “I have asked to see a priest...Is something that I have the need to do, to confess, commune and pray to God and Jesus Christ for everything to be fine...Of course I do not expect the nurse to be religious as I am and care for me religiously, but what she can do and I am expecting her to do is to provide the means to get this kind of care in here [hospital]” (F-68, PI-21, FG-1). “[...] When I felt that everything was hopeless, I did not care whether I received physical care by the nurses or not, prayer was then the only thing that was essential to me and which kept me from going insane. The nurses and the priest were there for me helping me to come closer to religion, to God. Praying, reading the Holy Bible took my mind off the constant thought that everything came to an end and that death was inevitable. I am sure now that it gave me hope and optimism for the future [...] I could not find any better words to describe quality nursing care than what the nurses did for me” (F-68, PI-25, FG-2)</p> <p>B. ‘When I pray it feels like I talk with</p>	<p>A.1.Caring for the patient religiously is considered as quality nursing care.</p> <p>A.2.Need for prayer, confession, commune.</p> <p>A.3.Patients rely on nurses to have their religious needs met.</p> <p>B.1.Need to</p>	<p>A. Addressing religious needs.</p> <p>B. Addressing spiritual</p>	<p>Nurses addressing patients’ religious and spiritual needs</p>

<p>God, I can express my fears and worries. In my state [referring to cancer] I can only request for His divine intervention for a miracle to happen....the priest helped me to understand the meaning of life...why we come to this world and where we go after death...all these have helped me a lot...Since we talked and better realised these things I feel a spiritual peace (M-58, PI-9).</p> <p>C. "Everything is so so "sterile" in this department. I get the feeling sometimes that the nurses do not like the sight of the priest coming to the ward [...] sometimes I have to ask them several times before they notify the priest, and when he is here staff makes him feel unwanted [...] as if he disturbs the ward tranquillity [...] that his presence was related to death or nearness to death, something that could provoke fear and upset. This is not fare for me and for the other patients wanting and needing to meet with the priest. Through his words I saw life in a different way, saw what Gods plan about me really was, he gave me a sense of relaxation, a spiritual "ease" that no one else managed to do" (F-21, PI-6, FG-2)</p> <p>D. "I hate it when the nurse acts as if all patients in the ward are the same. She does the same things for everyone, acting</p>	<p>communicate/connect with God.</p> <p>B.2. Understanding the meaning of life and death nurture the spiritual quest of the patient and bring spiritual peace.</p> <p>C.1. Negative perceptions about priests visiting the ward.</p> <p>C.2. Ward tranquillity is disturbed.</p> <p>C.3. Priest's presence connected to death or nearness to death.</p> <p>D.1. Nurses should care for the patients based on their individual needs.</p>	<p>needs.</p> <p>C. Barriers to the presence of priest on the ward.</p> <p>D. Holistic care that takes into consideration religious and spiritual</p>	
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<p>like a robot [...] she ought to know that we are different with different needs [...] All needs however are important and all needs demand satisfaction, some to a lower degree and some to a higher one [...] for me is important to have my privacy to pray without disruptions, speak with my priest or read a religious book, seeing my family and I expect her to do what is necessary to also have these needs met, is this not what quality nursing care really is? the nurse should be able to acknowledge these and respond appropriately” (M-21, PI-8, FG-1)</p>	<p>D.2. Respect the religious and spiritual needs of the patient.</p>	<p>needs.</p>	
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Table 17: Structural explication for nurses' response to the main theme "Nurses addressing patients' religious and spiritual needs"

Meaning Units (Condensed)	Sub – themes	Themes	Main Theme
<p>A. "It is a priority to meet his/her physical needs as best as we can, based on our knowledge, training and skills. However, I do not believe that this aspect of the care [meaning spiritual and religious care] is or should be a part of our job. I think that there are other people more specialised, such as the priests, better trained and prepared to provide such care for the patient and the family" (F-50, WMI-16).</p> <p>B. "Spiritual Care...? If you are referring to issues related to the religion then I think that we do anything possible to meet their needs. I do not mean personally care for them religiously because I would not know how to but making the necessary arrangements to allow this care to take place, might that be informing the priest to visit the patient or allowing time for his/her religious needs [...]" (M-39, WMI-11).</p> <p>C. "Hmm...(smiles). We are lucky if we can meet the 'more' important needs of the patients. We have to make sure that the patient is clean, fed, and he is given his medication and his chemotherapy,</p>	<p>A.1. Physical needs are seen as a priority by the nurses.</p> <p>A.2. Spiritual and religious care is not acknowledged as part of their nursing care.</p> <p>A.3. Nurses rely on others to provide spiritual and religious care to the patients [i.e. priest]</p> <p>B.1. Nurses misunderstand the term spiritual care. Spirituality and religion were used interchangeably.</p> <p>B.2. Indirect satisfaction of religious and spiritual needs.</p> <p>C.1. Nursing reliance on the bio-medical model obstructs the satisfaction of the religious and spiritual needs of the patients.</p>	<p>A. Nurses' beliefs on spirituality</p> <p>B. Nurses conceptualisation of spirituality.</p> <p>C. Restraints for spiritual and religious care.</p>	

<p>taken for his diagnostic tests or treatments [radiotherapy]. By the time we do all these, there is not enough staff or time for anything else [meaning spiritual and religious care]" (F-25, SNI-2) "I think that spirituality and religion is part of the holistic care. To be honest though we did not receive enough training [...] When I was in the nursing school very little if any time was devoted to spiritual care. This calls for changes to the curriculum, as for nurses to be better prepared. For us this training should be continued" (M-37, SNI-10) "The truth is that patients' spiritual and/or religious needs are not formally included in their care. I know that these needs are essential for the patient and should be addressed through specific nursing interventions; however it is up to me to find the ways to satisfy them. Unfortunately, this only happens with few nurses who have the knowledge [...]. Nursing assessment of patients' needs is dominated by the medical model, which is oriented primarily towards the physical needs, which does not promote any spiritual and religious care"(F-28, SNI-5)</p>	<p>C.2.Not enough time and staff to provide such care.</p> <p>C.3.Lack of adequate education.</p>		
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Table 18. Structural explication for the main theme “Being cared for in a nursing environment which promotes shared-decision-making”

Meaning Units (Condensed)	Sub-themes	Themes	Main Theme
<p>A. “Quality nursing care is all about choices to be made in collaboration with your carers and [Not participating in decision-making] is for me a negative aspect not only for the nursing care but for my health care in general. Things are simple to me, it will only take the health care professionals some time to provide us with more information that will allow me and the other patients to be involved in the decision – making process” (M-44, P1-18). “No I was not given the opportunity to participate in decision-making even though I wanted to...No one bothered, to explain to me what exactly I was about to do or what medication I was about to take....Last night I had nausea and asked them to give a specific medicine that I take at home, nurse X [name omitted] said no you can not take that one take this one that I am giving you....I told her that for me this medication is not effective and asked her the reason for giving me a different one, she said to me ‘because this one is better for you and the physician prescribed this one’, I was disappointed because she ignored me [...] as if they knew me better than myself” (F-58, P1-23)</p>	<p>A.1. Decision-making is part of the quality nursing care concept.</p> <p>A.2. Lack of opportunity to participate in decision – making processes and this is seen as a negative aspect of care.</p> <p>A.3. Difficult to participate without appropriate information.</p> <p>A.4. Lack of respect towards patients’ knowledge and appraisals.</p>	<p>A. Barriers to patient involvement in shared decision-making.</p>	<p>Creating a nursing environment to promote shared-decision-making</p>

<p>health care professionals can be evaluated if they are doing what they supposed to in involving patients in shared decision-making” (FG with PA).</p> <p>D. “I agree with my colleague and I would like to add that our society has allowed this approach to patient care. It is not something new but something that was generated in the people’s minds through the years. The icon of the health care professionals as ‘Gods’ was and unfortunately remains perhaps the most difficult barrier to overcome in the effort to introduce shared decision-making, and as a result it is considered as granted that the health care professionals should be taking all the decisions” (FG with PA).</p>	<p>D.1. The Greek-Cypriot society through salient messages accepts this situation in patient care.</p> <p>D.2. There is an icon of health care professionals as ‘Gods’ who know everything about the patients.</p>	<p>D. Cultural issues.</p>	
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Table 19. Structural explication for the nurses' response to the main theme "Being cared for in a nursing environment which promotes shared-decision-making"

Meaning Units (Condensed)	Sub-themes	Themes	Main Theme
<p>A. "Things are not black and white.... There is an important issue that I do not know if it had been brought up. What happens if the patient does not want to participate in such decisions? I am saying this because often I have offered the patients the choice to do or not do something [meaning bath, take meals, and choose a particular time to take a walk] but they left the decision to me...of course this does not apply for all the patients. Young patients tend to request for more participation in their own care and they have the right to...but what I do is not described in any policy and it is up to me if I want to do it or not" (M-27, SNI-3).</p> <p>B. "I agree with the views expressed by the patients, that rarely they have the chance to take an active role in their care, and be more autonomous even though it should be their right. Usually if not always we make the decisions for the patients making the assumption that they do not want to participate. We have been trained to be able to make these decisions and think that is our right and obligation</p>	<p>A.1. Nurses give choice to patients however; some patients do not take this opportunity and trust the nurse to choose for them.</p> <p>A.2. Respect patient preferences to participate or not in their own care.</p> <p>B.1. Motivation of health professionals to put shared decision - making into practice even if problems are identified for this effort.</p> <p>B.2. The perception that shared decision-making is a threat to professional autonomy.</p> <p>B.3. The belief that the nurse has the</p>	<p>A. Involving patients in SDM based on patient's preferences.</p> <p>B. Nurses attitudes towards SDM.</p>	<p>Quality nursing care relates to being cared for in a nursing environment which promotes shared-decision-making.</p>

<p>to" (M-54, WMI-19). "I do not mean to blame anyone...however from what I have been seeing is that health care professionals [referring to physicians and nurses] hold a certain view that they "know" what is best for the patient and want to have complete control....This reflects on what we can do for the patient to include them in their care decisions. This is the reason why the patients are not given these choices...of course as nurses we spend a lot of time with the patient and we try to give them some choices in relation to their daily activities...again however, the ward routine limits the choices" (F-22, SNI-1)</p> <p>C. "Quality nursing care relates to the patient increased involvement in his care. This may be shared decision-making or other strategies to increase their participation. However, it is difficult to involve the patients in the decision-making process. [...] sometimes there is not enough time or the support or the policy to engage them in this process. Personally, I am reluctant to involve my patients in SDM simply because I do not have the skills and did not receive the training to do it properly. I prefer not to take the risk...giving the patient no choice is the safe...trouble free way to care [...]"</p>	<p>knowledge and experience to make the best choices for the patient.</p> <p>C. 1. Before patients can participate in decision-making, nursing staff needs the relevant law to be adjusted.</p> <p>C.2. In the clinical setting there is little time to engage the patients in the decision-making.</p> <p>C.3. Lack of training required to involve patients in decisions.</p>	<p>C. Barriers to implementing SDM.</p>	
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The necessary information need to be supplied to them and at the same time the law should offer the nursing staff cover over decisions that are taken in collaboration with the patient” (F-35, SN1-9) “Speaking with my colleagues, especially the older ones, I get the impression that the Ministry and policy are the scapegoats for every problem that nursing is facing in Cyprus. Shared decision-making is one of these problems. The real reason for the difficulties in involving patients should be searched in the nurse’s behaviours and explicitly their resistance to SDM. They see SDM some kind of threat to their practice, I guess they are used to making all the decisions for the patient. They need training and support to be able to successfully involve the patients in decisions. Is the key to this problem [lack of participation in decision-making process]. It [policy] does not allow providing certain important information which would allow the patients to take such decisions. Without things changing in relation to policy, I do not see the way that things could change otherwise” (F-54, WM1-20).

Table 20: Structural explication for main theme “Patients being with and involving the family in the care”

Meaning Units (Condensed)	Sub – themes	Themes	Main Theme
<p>A. “To me quality nursing care is having my family with me during these difficult times in my life. Being there for me is the most important thing that gives me courage, and hope for the more difficult times to come and overcoming these. I mean assuring me that everything will be ok...that I will get over this [...] Please do not misunderstand me, I am not complaining for the care that the nurses give me, but the family is by nature closer to me, and this is something that a nurse can never do. (F-30, PI-12). When I am in the hospital I need a familiar and friendly face, a smile and a “sweet” word (<i>glikia lexi</i>) [...] You know just a boost or a support if you like.... (Small pause) to help me get through the day...one day each time. Is it much to ask?”(F-58, PI-II, FG-1). “Undoubtedly, family is the primary support that we can hope for when caring for patients with cancer. Most of the patients have good relationships with their families and therefore they benefit from their support [...] Simply their presence can be positive for the patient” (FG with PA)</p> <p>B. “I see the role of the family as</p>	<p>A.1. Quality nursing care is connected with having the family close when being cared for.</p> <p>A.2. Family members give the patient hope and courage.</p> <p>A.3. Family as a supportive mechanism.</p> <p>B.1. The family helps the patient</p>	<p>A. Being with the patient and emotionally supporting him/her.</p> <p>B. Family supporting</p>	<p>Patients being with and involving the family in the care</p>

<p>complimentary to that of the nurse for giving us quality nursing care and that is why I believe that they should work together for our benefit. Let's face it there are not enough nurses around all the time to care for us; this is where the family steps in to also care of us in any way they can. Besides this is what they do at home every day, I do not see the reason why they can not do it here as well in collaboration with the nurse. My husband helped me to get dressed, take my medicine and helped me to walkabout especially the first days after the operation; otherwise the nurse would be making these for me The nurses should realise the benefits and encourage family's involvement. (F-44, PI-13, FG-2). "I need my wife and children to be here with me and they have to be here to care for me even if this means just to give me a glass of water when I am thirsty [...] My children are educated and better understand the medical language and explain everything to me and together we decide what to do. The nurses do not always understand this and become strict with the visiting hours, not allowing them to stay longer or even at night. However, some of them bend the rules and allow them to stay outside visiting hours and sometimes try to involve them in the care, doing little things at the beginning and</p>	<p>with his/her everyday living needs.</p> <p>B.2. Involvement in the care and collaboration with the nurse.</p> <p>B.3. Family assuming role in communication with the nurse and the physician and participating in decision making.</p>	<p>patient's physical and informational needs.</p>	
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then becoming more involved. I am happy that I have them near me (M-68, P1-15).

then becoming more involved. I am happy that I have them near me (M-68, P1-15).			
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Table 21: Structural explication for nurses' response to the main theme "Patients' being with and involving the family in the nursing care"

Meaning Units (Condensed)	Sub – themes	Themes	Main Theme
<p>A. “I agree that part of providing quality nursing care it to involve the family in the care. Family and friends are of course important to the patient and specifically for his/her health condition. I have noticed that those who have the emotional support by their friends or family tend to have better health outcomes, getting better sooner than those who do not have this kind of support. [...] This support makes the patient feel calm and be more collaborative with us”. (M-31, SNI-6) “I am confident that the family and friends contribute to a better nursing, they fill in the gaps of our care; Therefore is important that we as nurses identify the significance of family and do more to get them involved-when I say get them involved I do not necessarily referring to specific things that they would be doing, to me giving them the chance to be with their patient is involvement” (F-51, WMI-18).</p> <p>B. “We do not have a problem from having them around, we need them to be there instead. On the contrary I have the opportunity to establish or strengthen my relationship with the patient and his/her family. Hence, I encourage them to spend more time with the patient, sometimes even outside visiting hours, but this is not always possible. If they want to get involved in the care then I give them the chance to be involved. It is more up to the patient in</p>	<p>A.1. Involving family and friends is part of the quality nursing care.</p> <p>A.2. Family’s contribution compliments the nursing care.</p> <p>A.3. Positive influence on health outcomes and relationship with nurses when receiving support from family.</p> <p>B.1. Family members were urged to spend time with the patient.</p> <p>B.2. Patient’s and family’s desire for family presence and involvement varies.</p> <p>B.3. Nurse-family</p>	<p>A. Nurses beliefs on family presence and involvement.</p> <p>B. Need for family presence and involvement.</p>	<p>Nurses agreed on the relatedness of family presence and involvement with quality nursing care.</p>

<p>he/she wants them around. Sometimes the patient does not want to have them around all the time; I guess they want some peace of mind. However, if we identify that the patient needs his wife, children or friends we try to satisfy this need any way we can [...] its human nature. When times are tough, we want to be with family and friends.” (F-45, WM-14) “Some of the relatives are quite skilful and experienced helping the patient since they are the ones who care for him/her at home as informal caregivers. Often they want to help in the hospital as well; doing the more practical things for the patient. Perhaps this makes them feel needed and helpful; they also feel that they are caring for their patient by being close to him/her.” (M-30, SNI-4). “Family is important to patients but also is important to us for many reasons. I see the family as an empowering force for the patients. I say this because with many of our patients not having the knowledge to understand the medical or nursing vocabulary or having a reduced comprehensive level rely on their relatives to be informed and take serious health decisions [...] Once the patient has gone home, it is his/her family that will assume the caregiver role, and for this to happen they need training. Being with the patient and involved this training can take place. Family can help us to deliver better care to the patient by solving these problems” (M-41, WM-15)</p>	<p>relationship influences family involvement.</p> <p>B.4. Family facilitates communication with the patient and decision making.</p> <p>B.5. Family training</p>		
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Appendix D

1. Patient consent form

MIDDLESEX UNIVERSITY
SCHOOL OF HEALTH AND SOCIAL SCIENCES

INFORMANT CONSENT FORM-PATIENTS

Centre Number:

Study Number:

Patient Identification Number:

Title of Project: Quality Nursing Care: patients' with cancer perspectives and the nursing response

Name of Researcher: Mr. Andreas Charalambous

Please initial box

1.	I confirm that I have read and understand the information sheet datedfor the above study and have had the opportunity to ask questions.	<input type="checkbox"/>
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	<input type="checkbox"/>
3.	I understand that sections of any of my medical notes may be looked at by responsible individuals from Middlesex University where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.	<input type="checkbox"/>
4.	I agree to take part in the above study.	<input type="checkbox"/>
5.	I prefer to be interviewed alone.	<input type="checkbox"/>

Name of Patient

Date

Signature

Researcher

Date

Signature

1 copy for patient; 1 copy for researcher

2. Patient information sheet

MIDDLESEX UNIVERSITY
SCHOOL OF HEALTH AND SOCIAL SCIENCES
HEALTH STUDIES ETHICS SUB-COMMITTEE

- **Study title**

Quality Nursing Care: patients' with cancer perspectives and the nursing response.

- **Invitation paragraph**

“Dear patient you are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this”

- **Purpose of the study**

The aim of the study is to investigate the views of patients with cancer as to explore their experiences and needs in term of nursing care in Oncology Departments. In the light of the patients' views, the nurses' and key informants' views will be explored according to the quality nursing care. The study is expected to be completed by the end of 2006.

- **Why have you been chosen?**

The research participants have been chosen purposively taking however, into consideration certain aspects of their care in order to present a sample that will include the various patients' categories. The research sample will be 25 patients, selected from the three hospitals. Additionally, when the interviews will be completed, 2 focus groups with the patients will be performed, one in each town (Limassol-Nicosia) and one focus group with the key informants.

- **Do you have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decided to take part you are still free to withdraw at any time and without giving a reason. A decision to withdrawn at any time, or a decision not to take part, will not affect you or your treatment in any way.

- **What will happen if you take part?**

If you are willing to take part, you will be interviewed if selected. It is important that your answers are honest and objective. If you are chosen to be interviewed, this will take place at your own room (oncology units) or at a specially prepared room if privacy can not be secured. However, you must be prepared to be available when the interview will take place. It is expected that the interview time will not exceed 45 minutes. Coffee and refreshment will be available during the interview. The researcher is expecting from you to sincerely provide answers and comments on the issue. The research method I will be using is hermeneutic phenomenology (qualitative research).

**MIDDLESEX UNIVERSITY
SCHOOL OF HEALTH AND SOCIAL SCIENCES**

▪ **What do you have to do?**

In the event that you are chosen to be interviewed or/and to participate in the focus groups, then you will be expected to be available when the interview/focus group will happen. You are expected to be sincere with your answers and comments.

▪ **What are the possible disadvantages of taking part?**

There are no disadvantages of taking part in this study. The opinions and answers of each participant are confidential and will remain confidential during and after the study. All the records (e.g. tapes) will be destroyed when the research will be completed.

▪ **What are the possible benefits of taking part?**

There is no intended benefit to you from taking part in this study.

▪ **Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you, which is used, will have your name and address removed so that you cannot be recognized from it.

▪ **What will happen to the results of the research study?**

The results of the research will be published in the ``*Cyprus Nursing Chronicles*``. If you are not a subscriber of the above magazine a copy of the results can be obtained from me upon request. Explicitly, I assure you that you will not be identified in any way in any publication\report.

▪ **Who has reviewed the study?**

The Health Studies Ethics Sub-committee (HSESC) of Middlesex University (U.K.) and the Ministry of Health (Cyprus) have reviewed this study.

▪ **Contact for further information**

Should you have any queries prior, during or after the study please do not hesitate to contact me:

Andreas Charalambous (Cyprus Nursing School)

Tel. 99693478

Email: AC671@mdx.ac.uk, a.charalambous@hotmail.co.uk

The researcher wishes to express his sincere thanks for taking part in this research study.

3. Nurse consent form

**MIDDLESEX UNIVERSITY
SCHOOL OF HEALTH AND SOCIAL SCIENCES**

INFORMANT CONSENT FORM-NURSE

Centre Number:
Study Number:
Nurse Identification Number:

Title of Project: Quality Nursing Care: patients' with cancer perspectives and the Nursing Response

Name of Researcher: Mr. Andreas Charalambous

Please initial box

1.	I confirm that I have read and understand the information sheet datedfor the above study and have had the opportunity to ask questions.	<input type="checkbox"/>
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	<input type="checkbox"/>
3.	I agree to take part in the above study.	<input type="checkbox"/>

Name of Nurse

Date

Signature

Researcher

Date

Signature

1 copy for nurse; 1 copy for researcher

4. Nurse information sheet

MIDDLESEX UNIVERSITY SCHOOL OF HEALTH AND SOCIAL SCIENCES

HEALTH STUDIES ETHICS SUB-COMMITTEE

- **Study title**

Quality Nursing Care: patients' with cancer perspectives and the nursing response.

- **Invitation paragraph**

"Dear colleague you are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this"

- **Purpose of the study**

The aim of the study is to investigate the views of patients with cancer as to explore their experiences and needs in term of nursing care in Oncology Departments. In the light of patients' and advocates views, nurses' perceptions will be explored in relation to quality nursing care.

- **Why have you been chosen?**

The research informants have been chosen conveniently taking however, into consideration different professional backgrounds (e.g. level of study) in order to present a sample that includes the various nurses' categories. The research sample will be 20 nurses, selected from the three hospitals.

- **Do you have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decided to take part you are still free to withdraw at any time and without giving a reason. A decision to withdrawn at any time, or a decision not to take part, will not affect your job in any way. What needs to be made explicit here is that a decision to take part will not provide any form of benefits to you or your working status.

- **What will happen if you take part?**

If you are willing to take part, you will be interviewed if selected. It is important that your answers are honest and objective. If you are chosen to be interviewed, this will take place at the hospitals, at a specially prepared room. However, you must be prepared to be available when the interview will take place. It is expected that the interview time will not exceed 40 minutes. Coffee and refreshment will be available during the interview. Again the researcher is expecting from you to sincerely provide answers and comments on the issue. The research method I will be using is hermeneutic phenomenology (qualitative).

**MIDDLESEX UNIVERSITY
SCHOOL OF HEALTH AND SOCIAL SCIENCES**

▪ **What do you have to do?**

In the event that you are chosen to be interviewed or to participate in the focus groups, then you will be expected to be available when the interview/focus group will happen. You are expected to be sincere with your answers and comments.

▪ **What are the possible disadvantages of taking part?**

There are no disadvantages of taking part in this study. The opinions and answers of each participant are confidential and will remain confidential during and after the study. All the records (e.g. tapes) will be destroyed when the research will be completed.

▪ **What are the possible benefits of taking part?**

There is no intended benefit to you from taking part in this study.

▪ **Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you, which is used, will have your name and address removed so that you cannot be recognized from it.

▪ **What will happen to the results of the research study?**

The results of the research will be published in the "*Cyprus Nursing Chronicles*". If you are not a subscriber of the above magazine a copy of the results can be obtained from me upon request. Explicitly, I assure you that you will not be identified in any way in any publication/report.

▪ **Who has reviewed the study?**

The Health Studies Ethics Sub-committee (HSESC) of Middlesex University (U.K.) and the Ministry of Health (Cyprus) have reviewed this study.

▪ **Contact for further information**

Should you have any queries prior, during or after the study please do not hesitate to contact me:

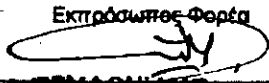
Andreas Charalambous (Cyprus Nursing School)


Tel. 99693478

Email: AC671@mdx.ac.uk, a.charalambous@hotmail.co.uk

The researcher wishes to express his sincere thanks for taking part in this research study.

5. Ethical Approval from the Ministry of Health and the HSESC

ΥΠΕΥΘΥΝΗ ΔΗΛΩΣΗ ΕΚΠΡΟΣΩΠΟΥ ΦΟΡΕΑ	
Η Διοίκηση του Φορέα και όλοι οι Συνεργάτες έχουν ενημερωθεί για το περιεχόμενο του ερευνητικού έργου με τίτλο «Η εφαρμογή της ικανοποίησης των νοσηλεύτων και των ασθενών ως δείκτης ποιότητας φροντίδας σε ογκολογικές μονάδες» και συμφώνησαν να συμμετάσχουν σε αυτό.	
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Α. ΤΡΥΦΟΝΙΔΗΣ	
(υπογραφή εκπροσώπου και σφραγίδα φορέα)	
Αριθμός Ταυτότητας	441381
Ημερομηνία	27.9.2004



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**Middlesex
University**

Andreas Charalambous
Research Student

16th March 2005

Dear Andreas,

Re: Quality Nursing Care: the oncology patients' perspectives and the nursing response.

Thank you for the response which adequately answers the ethics committee's queries. On behalf of the committee, I am pleased to give your project its final approval. Please note that the committee must be informed if any changes in the protocol need to be made at any stage.

I wish you all the very best with your project. The committee will be delighted to receive a copy of the final report.

Yours sincerely

Professor (I) Rena Papadopoulos
Chair of Ethics Sub-committee (Health Studies)

Appendix E

I. Patient narratives

To explore the lived experiences of patients with cancer in cancer care departments in relation to quality nursing care.

INTRODUCTION

Hi, (Ms/Mrs/Mr) (NAME), my name is Andreas Charalambous. Would it be alright if you could tell me about your experiences in relation to the nursing care you have received in (SITE OF CARE)? I am working on a study with cancer care departments to try to find out about the kind of nursing care patients are getting.

INTRODUCTION OF THE *PIS* AND THE *CONSENT FORM* TO THE PATIENT

***(Adequate time is provided to the patient to study the information sheet)**

Before we begin, I want to tell you that you do not have to answer my questions, though, if you do not want to, and you can stop at any time. Your doctors and nurses will still give you the best care possible whether or not you decide to participate in this study. This interview will be confidential, that is, your name will never be linked to your answers, but your answers will be combined with the answers of other patients to give useful information that might be beneficial to patients in the future. Your answers will not be shared with your health care team.

Is there anything that you would like to discuss before we begin our conversation?

Is it OK if I start?

Yes1 (continue)

No.....2 (can I come back another time that would be better for you?)

DEMOGRAPHIC DATA

I would like to start with some questions about your personal information.

1. Gender:
2. Marital Status:
3. Age:
4. Which district do you live?:
5. Occupation?
6. Level of education?
7. When where you first diagnosed with cancer?
8. Is this the first time you are nursed in this department? Yes/No If the answer is NO How many times have you been nursed in this department in the last year?
9. Days of stay/treatment in this cancer care department:
10. What is the diagnosis for your illness?

NARRATIVE OPENING QUESTION

1. What does the concept “quality nursing care” mean to you?

NARRATIVE STEM QUESTIONS (in random order)

1. What comes to your mind when you think of the term “Quality nursing care”?

- Looking for beliefs and values.
- Looking for cultural elements.
- Looking for personal meanings.
- Relate quality with issues such as ‘meeting physical needs’, ‘holistic care’ etc.

2. During your stay in the department what were the most important needs that you expected nurses to evaluate and meet?

- Looking for various needs that patients expect nurses to address, such as psychological, physical etc.
- Relate various needs with the term of ‘quality’.

3. During your treatment were you given the opportunity to participate / be involved in decisions pertaining your care and treatment?

- Opportunity to participate in decision making
- Whether the patient was offered a choice of care options
- Patient information and education
- Possible disappointment from the patient for not participating in decisions

4. Can you give me an example of Nursing Care that you received or witnessed others receiving such as a family member, friend or a neighbour when you thought “this is good Nursing Care”- Based on your example, what would you say is “Quality Nursing Care”?

- Look for factors which contribute to quality.
- Looking for personal meanings.
- Looking for descriptions and examples

5. Overall would you consider yourself pleased from the Quality of Nursing Care you are receiving in this department? Could you please justify your answer?

- Looking for personal opinions/experiences.
- Looking for factors that negatively or positively influence of nursing care.
- How important is satisfaction with nursing care for patients.

6. Please describe one incident from which you were satisfied from the Quality of the Nursing Care you received in this department (Giving the reasons for your answer).

- Looking for factors that positively influence quality of nursing care.
- Looking for factors such as the healthcare facilities condition (structure).
- The total nursing hours provided per patient (structure).
- Patient information and education (process).
- Length of stay (outcome).
- Holistic care (process).

7. Please describe one incidents from which you were not pleased from the Quality of Nursing Care in this department (Giving the reasons for your answers).

- Looking for factors that negatively influence quality of nursing care.
- Pain management (process).
- Assessment and implementation of patient care requirements (process).
- Responsiveness to unplanned patient care needs (process).
- Ratio of nursing staff per patient (structure).
- Nurse qualifications/skills (structure).
- Complications during treatment (outcome).

8. Would you say that the nursing care offered by the nurses can be improved? If the answer is YES. In your opinion what needs to be done in order to make the nursing care better?

- Personal opinions related to structure – process – outcome issues.
- Need for more information about their care.

9. Is there anything else you wish to discuss which relate to the quality of nursing care you have received and which we have not talked about?

- Whether the patient wished to change anything regarding his/her care.
- More participation in decision-making.
- Patients' views should be taken into account in decision making, both at the level of individual care and in issues of management and policy.

2. Nurse narratives

To explore the lived experiences of nurses caring for patients with cancer in cancer care departments in relation to quality nursing care.

INTRODUCTION

Hi, (Ms/Mrs/Mr) (NAME), my name is Andreas Charalambous. Would it be alright if I asked you some questions about the nursing care you provide since you have been working in this oncology department (SITE OF CARE)? I am working on a study with cancer care departments to try to find out about the quality of nursing care patients are receiving in these areas.

INTRODUCTION OF THE *NIS* AND THE *CONSENT FORM TO THE NURSE*

*(Adequate time is provided to the nurse to study the information sheet)

This is a voluntary interview and therefore, you do not have to answer my questions, if you do not want to, and you can stop the interview at any time. Your decision to participate or not in the study will not have any positive or negative effects on your job. The interview will be confidential, that is, your name will never be linked to your answers, but your answers will be combined with the answers of other nurses and patients to give useful information that might be beneficial to patients and nurses in the future.

Do you have any questions?

Is there anything else that you would like to discuss before we begin our conversation?

Is it OK if I start?

Yes1 (continue)

No.....2 (can I come back another time that would be better for you?)

DEMOGRAPHIC DATA

I would like to start with some questions about your personal information.

1. Gender:
2. Marital Status:
3. Age:
4. Which district do you live?
5. How many years have you been working in this cancer care department or in another cancer care department?
6. What is your rank?
7. What is your general educational background?
8. What are your nursing qualifications?

9. Have you received further training or education in cancer care nursing?
10. Which and where from?

NARRATIVE OPENING QUESTION

1. Patients and their advocates think “quality nursing care” in terms of:

- The availability and easy access to cancer services as related to quality nursing care.
- Communicating well with the nurses and receiving emotional support from them.
- Principles like autonomy, participation in decision making, and being adequately informed.
- Receiving care by competent nurses.
- Holistic caring which emphasises the spiritual and religious needs.
- Family closeness and involvement in the care.

What is your response to each of these perspectives expressed by the patients?

NARRATIVE STEM QUESTIONS (in random order)

1. What comes to your mind when you think of the term “quality nursing care”?

- Looking for beliefs and values.
- Looking for cultural elements.
- Looking for personal meanings.
- Looking for any similar responses with those of the patients (aide memoir)
- Relate quality with issues such as ‘meeting physical needs’, ‘holistic care’ etc (aide memoir).

2. Based on your experience in this department what were the most important needs that patients expected you to meet?

- In your opinion which of these needs were best addressed by you?
- In your opinion which of these needs were less addressed by you?
- Do you address the patients’ needs based on which they considered as the most important?
- How do you evaluate the importance of patients’ needs?

3. Patients in their narratives argued that *‘they rarely or never have the possibility to be involved in the decision-making process regarding their health related issues’*.

- What is your response to this statement?
- What are the reasons that inhibit patients to participate in the decision-making process?

- The hospital policy provides the opportunity to the patients to participate in decision making?
- What is opinion on the policy's guidelines regarding shared decision-making and the role of the nurse?
- Patient information and education.
- What are the consequences of this aspect of care - possible disappointment from the patient for not participating in decisions, low satisfaction?

4. Family and significant others are considered by patients one of the most important support mechanism they have during their course of illness. Nevertheless, based on patients' views and their advocates, they are not involved in their care as much as the patients and their family would like to.

- What is your response to this statement?
- What are the reasons that prevent family members to be involved in the care of their loved ones?
- Is the hospital policy facilitating or inhibiting such an involvement – visitation policy?

5. What methods are used (if used) by this organisation to assure the provision of quality nursing care to patients? Do you believe that these methods are effective in action or do they face some challenges? If so, which? Can you provide some possible responses to these challenges?

- Quality improvement processes and policies.
- What is reported regarding quality of nursing care?
- How is reported and to whom?
- How is this information used?
- Nurses accountability.

6. Would you believe that the level or the nature of the education and training that you have received was sufficient in order to address the patients' needs specifically and provide quality nursing care more generally?

- Does this organisation or the Ministry of Health provide you the opportunity for further training or education in cancer care nursing?
- Opportunities to develop clinical skills.
- Identify any personal and professional development needs which may help nurses to add to their skills in order to be able to respond in more effective, efficient and sensitive ways.

11. Is there anything else you wish to discuss which relate to the quality of nursing care and which we have not talked about?

3. Patients focus groups

Location: Limassol General Hospital and BOC Oncology Centre

Duration: 1-1:30 hours

Questions

In the narratives some of you and others not taking part in this focus group have described “quality nursing care” in various ways and in the following random terms:

- Needs satisfaction – focus on spiritual and religious needs.
- Receiving adequate information.
- Opportunity to participate in decision-making.
- Family closeness and involvement in the care.
- Communicating well with the nurses and receiving emotional support from them.
- Sense of safety.
- Nurses proximity.
- Nurses’ competency (medico-technical skills).
- Availability and accessibility of cancer services.

Would you agree that these terms are appropriate to define “quality nursing care”?

Another term used by patients to define “quality nursing care” was shared decision-making in health care decisions.

- Why shared decision-making is important to you?
- In what way would you like to participate in your health care decisions?
- How could we as nurses assist you for this?

In relation to the needs that you expected nurses to gratify during your treatment, you have reported the following:

- Physical needs – related to daily activities
- Spiritual needs.
- Religious needs.
- Emotional needs.
- Needs related to treatment (i.e. information giving, decision-making, participation).
- Social needs – family and significant others closeness and involvement in the care.

Do you believe that the nurses tailored your care in such a way in order to meet your individual needs or rather on a more general approach?

Did the nurses give more emphasis on a particular category of needs that you did not consider as so important during your treatment and if so why do you think this?

Since the aim of this study is to improve the quality of the nursing care provided to patients with cancer and based on your experience from the nursing care you have received over time, how could we improve the journey of patients with cancer through nursing care in cancer care departments?

4. Advocates focus groups

Location: Limassol

Duration: 1- hour

Question

In the narratives the patients have described “quality nursing care” in various ways and in the following terms:

- Needs satisfaction- with a focus on spiritual and religious needs.
- Being informed by the nurses.
- Being given the opportunity to participate in decision-making.
- Communicating well with the nurses and receiving emotional support from them.
- Nurses’ competency (medico-technical skills) which promotes a sense of safety when being cared for.
- Availability and accessibility of cancer services.
- Family closeness and involvement in the care.

Would you agree that these terms adequately define “quality nursing care” or there are more aspects of the concept that the patients failed to identify?

Appendix F

1. List of articles

- Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2008). Listening to the voices of patients with cancer and their nurses: a hermeneutic phenomenological study of quality Nursing Care. *European Journal of Oncology Nursing* (Accepted for Publication 9/05/08).
- Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2008). Meaning of 'quality nursing care' as narrated by patients with cancer. *Scandinavian Journal of Caring Sciences* (Send for Publication - SCS-2008-0078)
- Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2008). Have we overconceptualised the term quality nursing care: a selective literature review? *Journal of Advanced Nursing* (Send for Publication - JAN-2007-0620.R1).
- Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2008). Quality in Cancer Nursing Care. *Cyprus Nursing Chronicles*. (Accepted for publication-15/11/2007)
- Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2008). Ricoeur's hermeneutic phenomenology: an implication for nursing research. *Scandinavian Journal of Caring Sciences* (Accepted for publication-5/10/2007)
- Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2007). Quality Nursing Care, the perspectives of patients with cancer and the nursing response. *European Journal of Cancer*, 5(4), p422-423.
- Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2006). Quality Nursing Care: patients' perspectives and the nursing response (preliminary report). *European Journal of Oncology Nursing*, 10(3), p220.

2. List of Conference Presentations

- (04/2008) 7th European Regional Conference of the Commonwealth Nurses' Federation. *Improving the quality nursing care for patients with cancer in Cyprus: findings from a hermeneutic phenomenological study*. (Oral Presentation – Malta).
- (09/2007) ECCO 14– *Quality Nursing Care: patients' with cancer perspectives and the nursing response* (Oral Presentation - Spain-Barcelona).

- (05/2007) ISHR Summer Conference. *Quality nursing care: patients' perspectives and the nursing response*. (Poster Presentation - Middlesex University-London)
- (03/2007) 6th Commonwealth Regional European Nursing Conference. *Quality nursing care: patients' perspectives and the nursing response*. (Oral Presentation - RCN-London)
- (11/2006) 13th Pancyprian Nursing Conference – *Cancer Nursing: Patients' perspectives*. (Oral Presentation – Cyprus).
- (04/2006) 5th EONS Spring Convention – *Quality Nursing Care: Cancer Patient's Perspectives and the Nursing Response: Preliminary Report* (Poster Presentation - Austria-Innsbruck).
- (11/2005) 12th Pancyprian Nursing Conference – *Patients' and Nurses' Satisfaction as Quality Indicators*. (Oral Presentation – Cyprus).

3. Examples of Published Material

(A) Title:

Ricoeur's hermeneutic phenomenology: an implication for nursing research

Authors

- Andreas Charalambous,
- Professor (I)Rena Papadopoulos,
- Alan Beadsmoore

Funding / Sponsorship: N/A

Ethical Approval: N/A

Keywords: Hermeneutic Phenomenology, Paul Ricoeur, narratives, nursing, research, lived experiences

Scandinavian Journal of Caring Sciences (Accepted for publication-5/10/2007)

Abstract

Researchers and educators are increasingly implementing qualitative research methods to investigate issues of concern and interest. Hermeneutics has risen as an option for the qualitative research paradigm particularly after the 1970s. The precedence of the sciences that have applied hermeneutics as their approach to investigation is provided with special reference to nursing. In the nursing science, hermeneutics have been used extensively as a qualitative research method to investigate a variety of issues, through the lived experiences of the participants. In this paper we introduce important aspects of the philosophy of Paul Ricoeur and we discuss the reasons why we have applied this approach in our study titled "Quality Nursing Care: perspectives of patients with cancer and the nursing response". The arguments that are presented here can be generalized to fit other areas of Nursing Science. Through this paper our aim is not only to familiarize the reader with Ricoeur's work but also to arrive at an appreciation of his philosophy as a methodological approach for future nursing research.

Key words: Hermeneutic Phenomenology, Ricoeur, nursing research, Ricoeur's Interpretation Theory.

Hermeneutics in Nursing Science

Thompson (1) asserts that from the 1970s onwards there has been an increasing reference to hermeneutics in the methodological literature of the health sciences. Prior to this date, the discussions of hermeneutics were most commonly found in such disciplines as continental philosophy, theology, and literary criticism. Hermeneutics has emerged as a philosophy that redefines the scope and nature of the health sciences (2, 3, 4). Hermeneutics is recognised as a philosophy that supports an approach to health research which focuses on meaning and understanding in context. This methodological literature is part of a movement among practitioners and scholars in applied disciplines who have become dissatisfied with positivism as an adequate philosophical grounding.

As a consequence of the steady growth of interest that occurred in the 1980s, hermeneutics has emerged as a philosophy whose relevance extends beyond the humanities to the practice disciplines, and even to the natural sciences themselves (1)

The methodological and philosophical views of hermeneutics provide according to Finch (5) a 'new direction for study not only in philosophy but also across many disciplines, including nursing' (p 253). Through hermeneutics, the essence of beliefs, values and commitments can become known and clarified. This philosophical stance provides the explanations or perceptions which supports an individual's beliefs and provides the explanation of meaning. Finch (5) asserts that 'Each person brings to the hermeneutical moment a storehouse of pre-understanding derived from human experiences. Sometimes labelled as baggage of past experience, this pre-understanding provides the 'know-how' to deal with life's everyday events' (p 253).

A considerable precedent now exists for the concurrence of hermeneutics and health research. Database searching of research published shows that researchers in the disciplines of health sciences and particularly nursing have taken this approach: Walters (6), Cronin, (7), Lindseth, and Norberg, (4), Whitehead, (8), Fagerstrom *et al*, (9), Drapper, (10), Little, (11), Walsh and Kowanko, (12), Robertson, (13), Reed, (14), Finch (5), Wiklund *et al.*, (15) Koivisto *et al.*, (16) LeVasseur, (17).

The hermeneutics of Paul Ricoeur

'[For hermeneutics] it is... to seek in the text itself, on the one hand, the internal dynamic that governs the structuring of the work and on the other hand, the power that the work possesses to project itself outside itself and to give birth to a world that would truly be the 'thing' referred to by the text. This internal dynamic and external projection constitute what I call the work of the text. It is the work of hermeneutics to reconstruct this twofold work' (18, p. 17-18).

For Ricoeur, following Gadamer, we can no longer define hermeneutics or the theory of interpretation in terms of the search for the psychological intentions of another person

which are concealed behind the text, and if we do not want to reduce interpretation to the dismantling of structures, then what remains to be interpreted?' (19, p. 141). The answer according to Clark (20) is a Heideggerian one; the interpreter should aim to inhabit and understand the mode of being projected by the text 'For what must be interpreted in a text is a proposed world which I could inhabit and wherein I could project one of my own most possibilities. This is what I call the world of the text, the world proper to this unique text....Through fiction and through poetry, new possibilities of being-in-the-world are opened up within everyday reality' (19, p. 142 as cited by Clark)

The philosopher Gadamer's major contribution to philosophical hermeneutics is to have provided it with a general theory of human understanding. Ricoeur's vital contribution to the discipline is in his having drawn from this ontology of understanding methodological conclusions of direct relevance to the practice of the human sciences. In doing so, he has also addressed the key problem in the philosophy of the human sciences that Gadamer's hermeneutics tends to leave unresolved, namely, the problem of the relation between explanation and understanding (21, p. 326).

Ricoeur in his philosophical approach attempted to bridge ontological and critical hermeneutics which up to his time were considered incompatible. This incompatibility was based mainly on the genuine differences between the two. However Ricoeur proposed 'an alternative that aimed at unifying the most convincing aspects of them both' (22, p. 9).

Hermeneutics is the theory for which Ricoeur is most celebrated (23). In his early work *Symbolism of Evil*, Ricoeur saw hermeneutics merely as a method of interpreting symbols. However, he subsequently refined hermeneutics into a theory of interpreting discourse as a whole, including, but not confined to, the symbols which any discourse contained (24).

Ricoeur (18, 25) asserts that the process of interpreting texts does not involve the realisation or understanding the intentions of the narrator, but is to understand the meaning of the text itself; that is the directions of the thoughts that are opened up by the

text's elusive meaning. According to Wiklund *et al.*, (15) what is opened up, or appropriated, is the disclosure of possible ways of being in the world. Understanding of the text is to follow its movement from the manifest description (what the text says) to what it talks about. 'When following the text beyond the situation and the intentions of the author, and beyond the reader's situation, the text discloses possible modes of being in the world that can be appropriated (15, p. 115). Philosophically, this process of appropriation has its foundations in Gadamer's concept of tradition. Ricoeur (19) asserts that 'the action of tradition [effective- history] and historical investigation are fused by a bond which no critical consciousness could dissolve without rendering the research itself nonsensical' (p. 76).

According to Geanellos (26) it is 'through participation in the tradition in which we live we gain a sense of the familiar and of belonging. Tradition is not alien; it is something into which we have grown, something we have appropriated through engaged living' (p. 114). Ricoeur (25) as with Gadamer perceives appropriation as to "make one's own" what was initially "alien" which is the aim of hermeneutics (p. 185). According to Ricoeur (25) the process of interpretation comes to a closure 'when reading releases something like an event, an event of discourse, and an event in the present time' (p. 185). The result of this process provides the interpreter with a new perspective of things which allows him or her to view the world differently. Ricoeur (27) in his work 'On interpretation' explains 'that the condition for understanding and self-understanding is the linguistically mediated tradition to which we belong, the whole treasury of symbols transmitted by the cultures within which we have come, at one and the same time, into both existence and speech' (p. 192-3).

Ricoeur asserts that interpretation allows actualisation of the meanings of a text and this occurs through appropriation (19, p. 185). 'By 'appropriation', I understand this: that the interpretation of a text culminates in the self-interpretation of a subject who thenceforth understands himself better, understands himself differently, or simply begins to understand himself' (19, p. 158). Therefore the understanding of the text allows the interpreter to expand his horizons (i.e. to know him or herself). That according to

Geanellos (26) 'presupposes that we can distance our selves from our pre-understanding (distanciation) in order to perceive new meaning (appropriation)' (p. 117). 'Diastanciation' and 'appropriation' stand in a dialectical relation to one another and culminate in understanding (15, 26).

Ricoeur (19) addressed the difference between text and discourse, referring to these differences as distancing. The four principles of distancing are (a) the transcription itself and the meaning of the written word, (b) the relationship between what has been written and the intent of the person who wrote the text, (c) the meaning of the text beyond its original intent as well as the author's original intent, and (d) the new interpreted meaning of the written word and the audience. As described by Allen and Jensen (3, p. 245) the hermeneutical circle of interpretation moves forward and backward, starting at the present. It is never closed or final. Through rigorous interaction and understanding, the phenomenon is uncovered. The interpretive process that underlies meaning arises out of interactions, working outward and back from self to event and event to self.

Ricoeur (28) points out that 'Distanciation is not a quantitative phenomenon; it is the dynamic counterpart of our need, our interest, and our effort to overcome cultural estrangement. Writing and reading take place in this cultural struggle. Reading is the 'φάρμακο' (pharmako), the remedy, by which the meaning of the text is 'rescued' from the estrangement of distanciation and put in a new proximity, a proximity which suppresses and preserves, the cultural distance and includes the otherness within the ownness. (p. 43).

Wiklund *et al.*, (15) comment that by 'working within the text, distanciation as the dialectic counterpart of appropriation is possible' (p.117). The nature of the text holds within itself the foundations for distanciation as its characteristics objectify the text in several ways and give it a life of its own: it focuses on the 'what' of the text, rather than the empirical context. What Ricoeur attempts with the process of distanciation is to remove the authorial intent; that is according to Geanellos (26) 'the idea that the meaning of a text resides only with its author' (p. 113). The way in which the text is constructed to create the narrative will explain something about the text's meaning for

the reader. The meaning of the text, its sense, becomes more important than its reference, thus distanciation is not a methodological concern, a technique, but rather it 'is a constitutive of the phenomenon of the text as written' (28, p. 44).

The process of distanciation enables the interpreter to approach the text with an open mind and thereby appropriate its sense through the use of the explanations the text provides the reader with. Those explanations are directed towards a structural analysis of the internal relations of the text and to an analysis of deep structures that could be expressed as metaphors. The meaning of a text is its 'reference', but this is neither the psychological intention of the author nor an empirical state of affairs in the so-called 'objective' world ('ostensive reference'). The true referent of a text is what it is 'about', what Gadamer calls *die Sache*, the 'matter of the text' (19, p. 202).

Ricoeur calls this the 'world of the text'. He defines it as 'the ensemble of [non-situational] references opened up by the text' — as when we speak of the 'world of the Greeks', meaning thereby not an empirical reality but a particular understanding of the world. The 'intended meaning of the text' is the 'world' that it discloses; the projecting of a world is 'the process which is at work in the text' (19, p. 164)

According to Soderberg (29) Ricoeur replaced the term 'reference' for the term 'refiguration'. He writes about prefiguration, i.e. our pre-narrative world of lived experience; configuration, i.e. the sense narrated; and refiguration as equivalent to reference (30, 31). Fodor (32, p. 208) means that the terms referent and reference 'project a notion of the world as something static, fixed, given, whereas refiguration more adequately captures the dynamic connection between human action and human being-in-time, revelation, and transformation'.

Kearney (21) asserts that Ricoeur argued that the attempt to understand the specifically human must, in the final analysis, assume the form of a narrative: '...that human phenomena — texts, action — cannot properly be understood until the results of the explanatory approach have been integrated into a wider, interpretive understanding. (19, p. 8 as cited by Kearney)

The identification by Ricoeur that the narratives comprise the best approach (along with metaphors and symbols) to investigate people's lived experiences has informed our decision to implement this technique in this study as a means to collect the research data. Ricoeur (28) acknowledges that the person's lived experience retrieved through the narratives cannot directly become another person's experience. However, what can be transferred from one person to another is not the experience as experienced, but its meaning. Ricoeur (28) asserts that 'the experience as experienced, as lived, remains private, but its sense, its meaning, becomes public' (p. 16). The argument made here by Ricoeur describes the essence of this study; that is to make 'public' the meaning of the lived experiences of the patients with cancer and of their nurses.

Hermeneutic Phenomenology and Nursing Research

When the purpose of research is to search for the understanding of phenomena in the world of caring, it is necessary to reflect on ontological and epistemological concerns before choosing a methodological approach (15). In this process of choosing the most appropriate methodological approach as Wiklund *et al.*, (15) assert, the researcher needs to wonder not only about the 'phenomenon under study, but also about the relationship between explanation and understanding and whether the research method is consistent with the particular view of human nature that nursing imposes' (p. 1).

Nursing tends to view the person as one who is constantly interacting with the environment, interpreting impressions and ascribing personal meaning to his or her experiences (15, p. 114). The nurse researcher behaves in a similar way and therefore to claim that nursing is an 'objective science with one universal truth' (as Ricoeur asserts (23) is untenable. Here lays perhaps the most radical move, in the development of Ricoeur's theory, that of objectifying the text. Ricoeur removed the idea that the meaning of a text resides only with its author, which allowed 'researchers to move beyond the notion that only one understanding is meaningful or correct; that of the research participant' (26, p. 113). Therefore, this implies that the researcher has to take a

stance not only on the question of what knowledge is, but also on the appropriate way to attain that knowledge within the context of research.

We have implemented a hermeneutic phenomenology approach, inspired by the interpretation theory of Paul Ricoeur (25) in order to explore the perspectives of hospitalised patients with cancer on the quality of the nursing care. The decision to choose the hermeneutic phenomenological ideas of Ricoeur for this study was mainly based on four fundamental aspects. Firstly, Ricoeur's theory of interpretation, avoids the Cartesian subject/object split, thereby making it useful for the researcher seeking to explicate intersubjective knowledge. This aligned with our aim to seek to explore the issue of quality of cancer care holistically, focusing both on the experiences related to the body and mind of the patients and nurses. Cartesian thought clearly divided mind and matter, observer and observed, subject and object (33). Descartes (34, p. 97 as cited by Goldberg) argued 'there is a great difference between mind and body, in as much as body is by nature always divisible, and the mind is entirely indivisible.' (34, p. 447). This was appropriate for our identity as researchers that belong to the holistic nursing approach, which aims to overcome this Cartesian mental-physical split (35).

Secondly, Ricoeur asserts that 'interpretation is the hinge between language and lived experience' (28, p. 66). This is especially so with research interviews (i.e. narratives) and focus groups where lived experience is expressed through language then transcribed into a text and interpreted.

Thirdly, Ricoeur's hermeneutic approach takes into consideration the values, beliefs, and culture (i.e. *historicity* as Ricoeur calls it) of the specific context of the participants (and of the researcher) which are essential elements that need to be explored during the data collection and interpretation processes. Culture and its important influence on the interpretation of text might create a conflict of interpretations and therefore the selected approach needed to be able to address this potential problem. Hermeneutics explore the conflict of interpretations, because the possibility of 'very different, even opposing methods' of understanding is a fundamental aspect of our experience as interpreting beings (36, p. xiv-xv). The different modes of understanding and expression led Ricoeur

(28) to integrate in his work the creativity in language, and especially the semantic innovations of metaphor.

Finally, Ricoeur rejected the idea of bracketing allowing to the researcher to adopt a more active role in the interpretation process bringing into the study his/her experiences. Therefore, rather than suspending our preconceptions in this study, we were active participants in the interpretive process and not mere passive recipients of knowledge. We re-immersed ourselves into the participant's world by reflecting on our past and professional experiences with cancer patients. It was deemed impossible and less fruitful to the results of the study to position ourselves outside of the problem under study. This view is strengthened by Benner and Wrubel (37) who argue that researchers come to their studies with their own history, understandings and expectations.

The analyses of this study's narratives about being treated or providing care for cancer, focus on the meaning of lived experience, i.e. that each narrative contributes one person's perspective of the phenomenon. Therefore, according to Soderberg *et al.*, (38) the focus of analyses moves from the psychological understanding of the narrators (the utterer's meaning), to the meaning of their lived experience expressed in the text (the meaning of the utterance). What is analysed 'is what the text is saying and what it talks about' (28, p. 74).

Every decision taken by the researcher should be a reasoned one, reflect the theoretical framework of the methodology employed and be made explicit to others (39, 40). All research methodologies hold ideas about the nature of truth and reality, based on alternative epistemologies and ontologies. Researchers must be conversant with these and apply their interpretation of the theoretical framework to the research methods adopted (8).

The value of using a qualitative research methodology such as hermeneutics is embedded in the subjective and often emotional nature of the issue under study. The qualitative paradigm, with its emphasis on description, understanding and interpretation is appropriate for our study which aimed to investigate the quality of nursing care from

the viewpoints of patients with cancer and that of the cancer care nurses themselves (41). Hermeneutics has the ability to describe the human experience as it is lived and explores the full nature of the phenomenon (42). It is through hermeneutical inquiry according to Van De Zalm and Bergum (43) that practising nurses have the opportunity to find meaning in and understanding everyday situations with patients, to discuss and communicate their understanding with others, and as a result, to change their actions or the actions of others in subsequent situations on the basis of that understanding.

Conclusion

Reflecting on the research questions, the aims and objectives, the desired data, the literature review and the methods of research as a whole, hermeneutic phenomenology integrates all the necessary elements for conducting a successful qualitative study based on the lived experiences of the participants. The philosophical approach proposed by Ricoeur is considered to offer a deep, interpretive understanding of human experience.

In our study it seemed appropriate to explore the experience of the patients with cancer and the nurses involved in their care with the intent not solely to describe their experience, but to actually interpret it. It is believed that interpretation is required in order to understand human action (44). We believe that the basis of Ricoeur's philosophy is appropriate for nursing and the future nurse researchers can if they so choose take into consideration Ricoeur's work in their attempt not to reach for 'the one universal truth' but the 'many truths that the text hides' as Ricoeur was fond of saying.

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Introduction: Cancer remains a major cause of morbidity and mortality within Cyprus affecting one in four of the population. Alongside the nature of cancer has changed dramatically in recent years, including shorter inpatients stays, an increasing older cancer population and significant improvements in treatments outcomes and effectiveness. Despite the recent changes to service delivery, little attention in terms of the quality of health services has yet been focused on cancer patients and nurses. In light of these factors, the need to focus the exploration of the experience on those involved in the delivery and receipt of the care and its' potential value to nursing practice within the cancer care setting is important. Patients with cancer are better informed than before and have increasing expectations from the health care system. The pressures of this most educated, consumer-oriented generation will soon be felt in health care as they age and also begin to manage care on behalf of their parents.

Materials and methods: When searching for understanding the intricacies of the peoples' experiences, hermeneutic phenomenology presents itself as a useful philosophical approach, hence methodology, used for this research. Twenty-five patients and 20 nurses were purposively selected and interviewed through semi -structured interviews. The patients' opinions were validated through two focus groups. The key informants' opinions of the Cyprus Cancer Patients Associations were also explored through a focus group. The data analysis in this hermeneutic study was carried out in three stages: thematic analysis, analysis of exemplars, and the search for paradigm cases.

Results and discussion: The results indicate that patients stress the need for participation in the decision- making process, better communication with the carers, and holistic care emphasizing the increased need for emotional support. In terms of how patients define 'quality nursing care' they focus on issues related with the completion of

their needs, safety, trusting and qualified personnel. In terms of what they believe about cancer strong cultural themes emerged such as religion.

Conclusion: Safe conclusions can not be drawn at this point as the research study is yet incomplete. In the near future where all the interviews will be completed the nurses will be challenged to respond to the patients' opinions and areas of concern as part of an effort to generate possible ways of improving the satisfaction of the patient from the nursing care. However, the need for establishing better communication channels with the patients offering them all the necessary information that will enable them for shared-decision making is a problematic area where carers need to implement strategies as to improve the patients' experiences of the nursing care.

(C) Charalambous, A., Papadopoulos, R., Beadsmoore, A. (2007). Quality Nursing Care, the perspectives of patients with cancer and the nursing response. *European Journal of Cancer*, 5(4), p422-423.

Background: Cancer remains a major cause of morbidity and mortality within Europe of the 25. In Cyprus, a recent member of the European Community, cancer is affecting one in four of the population. Alongside the nature of cancer has changed dramatically in recent years, including shorter inpatients stays, an increasing older cancer population and significant improvements in treatments outcomes and effectiveness. Despite the recent changes to service delivery, little attention in terms of the quality of health services has yet been focused on patients with cancer and nurses. In light of these factors, the need to focus the exploration of the experience on those involved in the delivery and receipt of the care and its' potential value to nursing practice within the cancer care settings is important. This study came as a response to the current climate and it aimed to produce a National Service Framework for Cancer Nursing Care for patients with cancer underpinned by a theoretical model of what quality of nursing care is according to the Cypriot context.

Material and Method: In hermeneutics, the primary source of knowledge is the lived experiences of the participants (Ricoeur, 1981). Therefore, when searching for

understanding the intricacies of the peoples' experiences, hermeneutic phenomenology presents itself as a useful philosophical approach, hence methodology, used for this research. Twenty-five patients and twenty nurses were purposively selected and interviewed through narrative interviews and focus groups. The key informants' perspectives of the Cyprus Cancer Associations were also explored through a focus group. The data analysis in this hermeneutic study was carried out with a modified version of Ricoeur's Interpretation Theory

Results and Discussion: The results indicate that patients stress for comprehensiveness, recognition, need for participation in the decision-making process, better communication with their carers, patient-centred and holistic care emphasising the increased need for emotional support. In terms of how patients define 'quality nursing care they focus on issues related with the satisfaction of their needs, safety, proximity, trusting and being cared by qualified and competent nurses. In terms of their beliefs in relation to cancer, many cultural and social themes emerged such as religion, stigma, taboo and prejudice. Nurses on the other hand in their views on quality of nursing care' focused more on the physical needs of the patients and the technical aspects of the care they delivered.

Conclusion: The data analysis allowed the identification of certain practices that improve the quality of the nursing care provided to patients with cancer. From these a National Service Framework was structured. Furthermore in the light of the views of the patients and nurses on what constitutes quality nursing care' a theoretical framework was established.

(D) TITLE

Quality in Cancer Nursing Care

Ποιότητα νοσηλευτικής φροντίδας για ασθενείς με καρκίνο

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Περίληψη

Αυτό το άρθρο είναι μέρος μιας ποιοτικής μελέτης που αναλήφθηκε από το διαπολιτιστικό κέντρο για την έρευνα στον τομέα της υγείας του πανεπιστημίου του Middlesex. Ο στόχος της μελέτης ήταν να ερευνηθεί το ζήτημα της παροχής ποιοτικής φροντίδας στις υπηρεσίες καρκίνου της Κύπρου. Αυτό το άρθρο περιγράφει εν συντομία τα ζητήματα της παροχής ποιοτικής φροντίδας από τις νοσηλευτικές υπηρεσίες καρκίνου στο τρέχον κυπριακό πλαίσιο. Οι διαφορές μεταξύ της ‘ποιότητας της ζωής’ και της ‘παροχής ποιοτικής νοσηλευτικής φροντίδας’ συζητούνται προσφέροντας στον αναγνώστη τους θεμελιώδεις λόγους για τους οποίους αυτοί οι δύο όροι δεν πρέπει να συγχυσθούν. Μέσω της βιβλιογραφικής ανασκόπησης και των συμπερασμάτων της μελέτης, ορισμένες στρατηγικές που μπορούν να αντιμετωπίσουν το ζήτημα της ποιότητας στις υπηρεσίες καρκίνου προτείνονται.

Abstract

This article is part of a qualitative study which was undertaken by the Transcultural Centre for research in health of Middlesex University. The aim of the study was to investigate the issue of quality nursing care in the Cyprus cancer care services. This article briefly describes the issues of ‘quality nursing care’ and cancer in the current Cypriot context. The differences between ‘quality of life’ and ‘quality nursing care’ are discussed offering to the reader the fundamental reasons why these two terms should not be confused. Through the literature review and the study’s findings, certain strategies that can address the issue of quality in cancer services are proposed.

Εισαγωγή

Ο καρκίνος παραμένει μια σημαντική αιτία νοσηρότητας και θνησιμότητας στην Κύπρο και έχει προσδιοριστεί ως σημαντικό ζήτημα δημόσιας υγείας που επηρεάζει έναν στους τέσσερις από τον πληθυσμό (Υπουργείο υγείας, 2003). Παράλληλα με τη φύση του καρκίνου που έχει αλλάξει εντυπωσιακά τα τελευταία χρόνια, έχει επίσης περιορισθεί ο

χρόνος παραμονής των ασθενών, ενώ οι υπηρεσίες υγείας βρίσκονται τώρα αντιμέτωπες με ένα αυξανόμενο πληθυσμό ατόμων με καρκίνο (κυρίως εξαιτίας της αύξησης του προσδόκιμου της ηλικίας). Επιπρόσθετα, έχουν επιτευχθεί σημαντικές βελτιώσεις στις εκβάσεις και την αποτελεσματικότητα των θεραπειών (Pearce και συνεργάτες, 2001). Εντούτοις, παρά τις πρόσφατες αλλαγές στην παροχή υπηρεσιών, λίγη προσοχή από την άποψη της ποιότητας έχει στραφεί στους φορείς παροχής υπηρεσιών (νοσηλευτές) και τους χρήστες υπηρεσιών (ασθενείς με καρκίνο). Λαμβάνοντας υπόψη αυτούς τους παράγοντες, η ανάγκη να στραφεί η διερεύνηση της εμπειρίας εκείνων που περιλαμβάνονται στην προσφορά (νοσηλευτές) και την παραλαβή (ασθενείς) της φροντίδας και της πιθανής αξίας της στην πρακτική περιποίησης μέσα σε ένα πλαίσιο για την ρύθμιση της παροχής ποιοτικής φροντίδας καρκίνου είναι σημαντική.

Η Κύπρος έχει ένα μικτό σύστημα υγειονομικής περίθαλψης, όπου οι ασθενείς και το κοινό διατηρούν το δικαίωμα επιλογής ανάμεσα στον δημόσιο και τον ιδιωτικό τομέα για την λήψη φροντίδας (Πολυνείκης, 2006). Εκείνοι που επιλέγουν να πληρώσουν για τις υπηρεσίες που θα λάβουν με την πάροδο του χρόνου επιθυμούν να ενημερώνονται περισσότερο για την πραγματική αξία και την ποιότητα της υπηρεσίας που πρόκειται να λάβουν για τα χρήματά τους. Στην Κύπρο η πλειοψηφία των υπηρεσιών που αφορούν την φροντίδα ασθενών με καρκίνο προσφέρεται από το κράτος με αποτέλεσμα το μεγαλύτερο ποσοστό των ασθενών να χρησιμοποιούν τις κρατικές υπηρεσίες για την νοσηλεία τους. Ο κυρίως λόγος αυτού του φαινομένου είναι οι περιορισμένες υπηρεσίες που είναι διαθέσιμες στο πλαίσιο του ιδιωτικού τομέα όσον αφορά συγκεκριμένες ασθένειες όπως είναι η περίπλοκη ιατρική και νοσηλευτική φροντίδα που απαιτείται από τους ασθενείς με καρκίνο (Αλεξανδρινού, 2005). Αυτό απεικονίζει την πίεση μεταξύ του ιδιωτικού και δημόσιου τομέα στην Κύπρο και τι αυτή η κατάσταση υπονοεί. Τα πιο πρόσφατα αποτελέσματα αυτής της κατάστασης ήταν η μετατόπιση καταρτισμένων νοσηλευτών από τον ιδιωτικό στον κρατικό τομέα που δημιουργεί ένα τεράστιο πρόβλημα έλλειψης προσωπικού το οποίο θέτει σε κίνδυνο τη θεραπεία των συγκεκριμένων ομάδων ασθενών (Καρακατσάνη, 2005; Τυρίμου 2005). Η φυγή νοσηλευτών προς τον κρατικό τομέα έχει σχέση κυρίως με τις ελκυστικότερες συνθήκες

εργασίας που προσφέρονται (π.χ. καλύτερες μισθολογικές απολαβές, καλύτερες ευκαιρίες προαγωγής, αίσθημα ασφάλειας).

Το υψηλό επίπεδο της επαφής με το κρατικό σύστημα παροχής φροντίδας, τα αυξανόμενα επίπεδα φορολογίας, τα αποτελέσματα της ιδιότητας μέλους της Κύπρου στην Ευρωπαϊκή Ένωση, και η εκτενής συζήτηση για τη νομοθεσία και τα μεμονωμένα δικαιώματα των ατόμων (και κατ' επέκταση των ασθενών) έχουν καταστήσει τον κυπριακό πληθυσμό ενήμερο για τον τύπο των υγειονομικών υπηρεσιών που του παρέχονται, το επίπεδο πόρων που ξοδεύονται ή πρέπει να ξοδευτούν, και το επίπεδο ποιότητας της φροντίδας που λαμβάνουν από τις υπηρεσίες παροχής φροντίδας.

Ανεξάρτητα από τα γεγονότα αυτά, το ζήτημα της παροχής ποιοτικής φροντίδας δεν έχει συζητηθεί με οποιοδήποτε συστηματικό τρόπο στην Κύπρο. Αυτήν την περίοδο στην Κύπρο, δεν υπάρχει μια εθνική στρατηγική η οποία να αντιμετωπίζει το ζήτημα της παροχής ποιοτικής νοσηλευτικής φροντίδας. Το ζήτημα της ποιότητας αντιμετωπίζεται σήμερα απλώς ως ιατρική ανησυχία από το υφιστάμενο και τα μελλοντικά προγράμματα ανάπτυξης του Υπουργείου Υγείας (Πολυνείκης και Καλός, 1992).

Εντούτοις, σε μια ποσοτική έρευνα που έχει πραγματοποιηθεί στην Κύπρο και έχει συμπεριλάβει τις κυριότερες ογκολογικές μονάδες από τους Χαραλάμπους και Παπασταύρου (2006) έχει βρεθεί ότι η ποιότητα της νοσηλευτικής περίθαλψης γενικά και πιο συγκεκριμένα αυτή των υπηρεσιών καρκίνου απασχολεί τους ασθενείς, τις οικογένειες και τους φίλους τους. Αυτή η ανησυχία εκ μέρους του κοινού έχει οδηγήσει σε μια μεγάλη ιδιωτική πρωτοβουλία ώστε να καθιερωθούν διάφοροι σύνδεσμοι καρκίνου στο νησί σε μία προσπάθεια να προωθηθεί η ποιότητα της παροχής φροντίδας σε άτομα με καρκίνο τόσο στο νοσοκομείο όσο και στην κοινότητα.

Η αυξανόμενη ανάγκη και οι μειωμένοι πόροι έχουν φέρει την ποιοτική πτυχή της φροντίδας στο προσκήνιο. Οι χρήστες των υπηρεσιών υγείας είναι περισσότερο από ποτέ ενημερωμένοι γεγονός που οδηγεί και σε αυξημένες προσδοκίες. Οι πιέσεις αυτής της πιο μορφωμένης και καταναλωτικά-προσανατολισμένης γενιάς άρχισαν να γίνονται

πιο αισθητές στις υπηρεσίες υγείας δεδομένου ότι γερνούν και αρχίζουν να διαχειρίζονται την φροντίδα των γονέων τους. Η ιεραρχική και πατερναλιστική σχέση μεταξύ της υπηρεσίας και του ασθενή πρέπει να δώσει τόπο σε μια υγειονομική περίθαλψη η οποία θα αναγνωρίζεται ως βασικό ανθρώπινο δικαίωμα και οι ασθενείς θα αντιμετωπίζονται ως ανεξάρτητες οντότητες, με τις υπηρεσίες υγείας να διαμορφώνονται για να ικανοποιήσουν τις ανάγκες των ασθενών, των οικογενειών και των φροντιστών τους (Department of Health, 2004).

Η παραδοσιακή φροντίδα οδηγείται ως επί τω πλείστο από τον σχεδιασμό των νοσοκομείων και τις διαδικασίες φροντίδας και περίθαλψης, ένα γεγονός που έχει χαρακτηριστεί ως μια μη σχεδιασμένη περιπέτεια του ασθενή (Kingston Hospital, 1993). Υπάρχει μια κατάχρηση της εξουσίας που περιορίζει τη δυνατότητα του ασθενή να συμμετέχει στις αποφάσεις για την περίθαλψη και φροντίδα του / της. Η βελτίωση της εμπειρίας του ασθενή στο νοσοκομείο είναι η θεμελιώδης αρχή πίσω από την εισαγωγή του όρου «ποιότητα φροντίδας με επίκεντρο τον ασθενή –patient centre quality». Η ποιότητα έχει μετασχηματιστεί μέσω της διάβασης του χρόνου από μια μονοδιάστατη έννοια σε μια δυσδιάστατη έννοια τονίζοντας για την ανάγκη παραγωγής ενός καινοτόμου όρου που παράγεται από την ανάγκη να εξεταστεί η δυσδιάστατη φύση της ποιότητας. Αυτός ο ορισμός βασίζεται στην βιβλιογραφία που υποστηρίζει το γεγονός ότι ο ασθενής θα πρέπει να αποτελεί το κέντρο του συστήματος υγειονομικής περίθαλψης. Η άλλη πτυχή της ποιότητας, αυτή του νοσηλευτή-προμηθευτή μπορεί να καθοριστεί από τον όρο «ποιότητα φροντίδας με επίκεντρο τον νοσηλευτή –patient centre quality».

Ανασκόπηση της βιβλιογραφίας

Όταν κάποιος επιθυμεί να εξερευνήσει τον κόσμο του ασθενή προκειμένου να τον κατανοήσει υπό μια βαθύτερη έννοια, υπάρχει δυσκολία να το περιγράψει χωρίς τη μείωση του περιεχομένου του στο πλαίσιο εννοιών (Ericsson, 1997). Ο Von Wright (1995), επισημαίνει ότι μια διαστρεβλωμένη εικόνα της πραγματικότητας εμφανίζεται εάν κάποιος προσπαθεί να επιτύχει μεγαλύτερη ακρίβεια από ότι η φύση του φαινομένου επιτρέπει. Ένας σύνθετος κόσμος δεν μπορεί να εξηγηθεί με ακριβείς

όρους. Μπορεί μόνο να γίνει κατανοητός σε ένα ευρύτερο πλαίσιο. Μια μελέτη που διεξήχθη από τον Ericsson (1997), έδειξε ότι υπάρχει ένας κόσμος φροντίδας. Αυτός ο κόσμος φαίνεται διαφορετικός από την διάσταση του ασθενή και του νοσηλευτή, όπου ο κόσμος του ασθενή ξεχωρίζει ως κόσμος από άτομα που υποφέρουν. Αυτή η προοπτική επιβεβαιώνει το γεγονός ότι η ποιότητα της νοσηλευτικής φροντίδας ερμηνεύεται διαφορετικά μεταξύ των νοσηλευτών και των ασθενών, δείχνοντας με αυτόν τον τρόπο ότι τα δύο μέρη δεν συμμερίζονται τις ίδιες ανησυχίες και προτεραιότητες. Προκειμένου να προσφερθεί η αναγκαία ποιοτική φροντίδα, οι νοσηλευτές πρέπει να δουν τις απόψεις του ασθενή υπό μια βαθύτερη έννοια και με γνώμονα την μοναδικότητα που χαρακτηρίζει κάθε ασθενή (Ericsson, 1992). Συνειδητοποιούμε τώρα περισσότερο από ποτέ ότι η κλινική άσκηση και οι κλινικές αποφάσεις δεν μπορούν να βασίζονται μόνο στην επιστημονική γνώση. Είναι απαραίτητο αλλά μη ικανοποιητικό. Χρειάζεται να εισαχθούν επιπρόσθετες παράμετροι έτσι ώστε στις αποφάσεις να λαμβάνονται υπόψη και αυτά που θέλουν οι ασθενείς και είναι ευεργετικό για αυτούς. Ο χρόνος είναι αρκετά ώριμος έτσι ώστε να εγκαταλειφθεί η εγωιστική προσέγγιση που υιοθετείται όχι μόνο από τους νοσηλευτές αλλά από άλλους επαγγελματίες υγείας ότι *‘γνωρίζουμε τα πάντα σχετικά με τους ασθενείς και τις ανάγκες τους’*.

Μετά από την ανασκόπηση της σχετικής βιβλιογραφίας έγινε προφανές ότι υπάρχει έλλειψη ποιοτικών μελετών που να διερευνούν ολιστικά τις αντιλήψεις και την εμπειρία εκείνων που εμπλέκονται στην παράδοση και την παραλαβή των υγειονομικών υπηρεσιών. Οι υπάρχουσες μελέτες έχουν διερευνήσει το ζήτημα της ποιότητας από μια μονόπλευρη γωνία και με τη χρησιμοποίηση της ικανοποίησης ως βάση για τις μετρήσεις τους, αποτυγχάνοντας να απεικονίσουν την ολιστική φύση του φαινομένου (Macilfattrick και συνεργάτες, 2003 Mackay & Risk, 2001 Redfern & Norman, 1999 Oermann & Huber, 1999). Επιπλέον, οι περισσότερες μελέτες για την ποιότητα της φροντίδας περιορίζονται από το γεγονός ότι δεν παρέχουν την εννοιολογική ανάλυση του ορισμού της «ποιοτικής νοσηλευτικής φροντίδας» ενώ τα αποτελέσματα των μελετών υπονοούν ότι ερευνούν την «ποιότητα της υγειονομικής περίθαλψης» γενικά και όχι την «ποιότητα νοσηλευτικής φροντίδας» ειδικά. Εντούτοις, η έλλειψη διευκρίνισης του καθορισμού και της ορολογίας σε αυτές τις έρευνες προσκρούει επάνω

στη δυνατότητα να μετρηθούν οι πραγματικές εκβάσεις και τα αποτελέσματα της ποιότητας (Langton και συνεργάτες, 2003).

Όσον αφορά την φροντίδα ασθενών με καρκίνο όπου ζητήματα όπως η ποιότητα της παρεχόμενης φροντίδας, του σεβασμού στις προτιμήσεις του ασθενή και της ενεργής συμμετοχής του στις αποφάσεις θεραπείας είναι αρχικής σπουδαιότητας. Ο ρόλος της νοσηλεύτριας είναι απαιτητικός και υπάρχει μια αυξανόμενη ανάγκη να αντιμετωπίζονται οι ασθενείς ως συνεργάτες και ως ανεξάρτητα ανθρώπινα όντα. Υπάρχουν πολλά τεκμηριωμένα στοιχεία που υποστηρίζουν την στρατηγική συνεργασίας ανάμεσα σε νοσηλευτή-ασθενή στην παροχή ποιοτικής φροντίδας ασθενών με καρκίνο (Sowden και συνεργάτες., 2001 Coulter και συνεργάτες, 1999). Η δυνατότητα των ασθενών που πάσχουν με καρκίνο να ελέγξουν τα συμπτώματα της νόσου και η διατήρηση ενός ικανοποιητικού βαθμού ποιότητας ζωής είναι περιορισμένη λόγω έλλειψης της απαραίτητης γνώσης, της καθοδήγησης, και των οδηγιών από τους προμηθευτές των υπηρεσιών της υγείας και ιδιαίτερα τους νοσηλευτές, οι οποίοι συνήθως αποφεύγουν τη μεταβίβαση της ευθύνης για τη θεραπεία και την φροντίδα στον ίδιο τον ασθενή (Le Var, 2002). Περισσότερο σημαντικό όμως είναι οι ίδιοι οι ασθενείς να προετοιμαστούν για να αναλάβουν έναν ενεργό ρόλο στη θεραπεία τους (Coulter, 2002).

Διακρίνοντας τους ορισμούς της «ποιότητα της ζωής» και της «ποιότητα της νοσηλευτικής φροντίδας»

Για να είναι εφικτή η αντιμετώπιση των ζητημάτων της ποιότητας είναι σημαντικό καταρχήν να διευκρινισθούν οι δύο κύριοι ορισμοί που είναι σχετικοί με την φροντίδα ατόμων με καρκίνο. Ο πρώτος αφορά την «ποιότητα της ζωής» των ασθενών και των φροντιστών τους και ο δεύτερος αφορά την «ποιότητα της νοσηλευτικής φροντίδας» ο οποίος προσφέρεται από τις υπηρεσίες υγείας. Πολύ συχνά αυτές οι δύο πτυχές συγχύζονται μεταξύ τους και μπορεί να χρησιμοποιηθούν ακόμη και ως ταυτόσημες έννοιες. Αυτό έχει ως αποτέλεσμα οι δυο έννοιες να χάνουν την ακριβή τους σημασία και συνεπώς και των πρακτικών εφαρμογών τους. Η «ποιότητα της ζωής» στην

υγειονομική περίθαλψη αναφέρεται συχνά ως κλινική έννοια, και στο παρελθόν έχει μετρηθεί με όρους και προτεραιότητες που απεικονίζουν περισσότερο τις απόψεις των γιατρών παρά εκείνες των ασθενών (Oertmann, 1999). Εντούτοις, «η ποιότητα της ζωής» θα έπρεπε να αναφέρεται περισσότερο στις προσδοκίες και τις αντιλήψεις των ασθενών και των φροντιστών τους σχετικά με την φροντίδα. Η δεύτερη πτυχή της ποιότητας σχετίζεται με την ποιότητα της νοσηλευτικής φροντίδας και φαίνεται ότι δεν υπάρχει καμία συναίνεση όσον αφορά τον καθορισμό του όρου. Η ασάφεια της έννοιας «της ποιότητας» και του υπερμεγέθους του στόχου που επιβάλλεται επάνω στους επαγγελματίες υγείας έχει κάνει τις προσπάθειες να καθοριστεί η έννοια ιδιαίτερα δύσκολες και πολύπλοκες ενώ οι υπάρχοντες ορισμοί αντανακλούν στις περισσότερες περιπτώσεις την θέση του εκάστοτε ερευνητή. Επομένως ο καθορισμός της «ποιοτικής νοσηλευτικής φροντίδας» που συστήνεται εδώ πρέπει να διαβαστεί υπό το φως αυτών των παραμέτρων. Σύμφωνα με τις Redfern και Norman (1999) «είναι η αποδοτικότητα της νοσηλευτικής φροντίδας, η οποία θεωρείται ως ένας συνδυασμός από αξίες και δείκτες της κατάστασης της υγείας, μέσα στο πλαίσιο της διατήρησης ή της βελτίωσης της υγείας του ασθενή». Φυσικά, η ποιότητα της ζωής και η ποιότητα της νοσηλευτικής φροντίδας είναι λογικά στενά συνδεδεμένες έννοιες: η ποιότητα της νοσηλευτικής φροντίδας που προσφέρεται από τις υπηρεσίες υγείας πρέπει να αντανακλάται άμεσα στις εμπειρίες ποιότητας ζωής του χρήστη, και αντίστροφα η ποιότητα της ζωής των χρηστών θα πρέπει να επηρεάζει τις αλλαγές στις υπηρεσίες υγείας. Η ποιότητα της νοσηλευτικής φροντίδας σχετίζεται πρώτιστα με την *δομή* και τις *διαδικασίες* των υγειονομικών παρεμβάσεων ενώ η ποιότητα της ζωής αντιπροσωπεύει πρώτιστα την *έκβαση*, χρησιμοποιώντας τη γλώσσα της αξιολόγησης υγειονομικής περίθαλψης που εισηγήθηκε ο Donabedian (Monroe & Oliviere, 2003).

Πιθανές στρατηγικές για επίλυση του προβλήματος

Στην σχετική βιβλιογραφία έχουν αναγνωρισθεί διάφοροι λόγοι που επηρεάζουν την παροχή ποιοτικών υπηρεσιών στους ασθενείς και οι οποίοι σχετίζονται με τη μεταβαλλόμενη εποχή στα συστήματα υγειονομικής περίθαλψης σε όλο τον κόσμο. Σε αυτή την μεταβαλλόμενη εποχή η έννοια της ενδυνάμωσης των ασθενών εισάγεται στα

συστήματα υπηρεσιών υγείας λαμβάνοντας τη μορφή συμμετοχής των ασθενών σε διάφορες πτυχές της θεραπείας και φροντίδας τους (Wensing & Elwyn, 2002). Υπό αυτήν τη μορφή, η δυνατότητα επιλογής και η αυτονομία στους ασθενείς καθιέρωσαν μια βάση μέσα στο παράδειγμα της εξατομικευμένης φροντίδας. Αυτή η στρατηγική επιδίωξε να θεραπεύσει τις πρακτικές εκείνες οι οποίες βασίζονται στις στερεότυπες και προσανατολισμένες προς την εργασία προσεγγίσεις. Ο Woodward (1998) υποστηρίζει ότι οι νοσηλεύτριες χρειάζεται να επικεντρώσουν την φροντίδα στις εξατομικευμένες ανάγκες, απόψεις και προτιμήσεις των ασθενών αναγνωρίζοντας τις μοναδικές εμπειρίες του ατόμου, οι οποίες θεωρούνται ως κεντρικός σκοπός της κλινικής διακυβέρνησης (clinical governance). Σύμφωνα με τους Wensing & Elwyn (2002) πρέπει να αποτελεί ηθικό και νομικό κανόνα οι ασθενείς να ενημερώνονται και να συμμετέχουν στην υγειονομική περίθαλψή τους, τουλάχιστον ως μέρος ελάχιστα καθορισμένων πρότυπων και ως ένα ορισμένο βαθμό.

Η συμμετοχή των ασθενών και του κοινού στην παροχή φροντίδας σχετίζεται με την οικοδόμηση σχέσεων εμπιστοσύνης με τους ανθρώπους (DoH, 2003). Η επιτυχής συμμετοχή συνεπάγεται μια μετατόπιση δύναμης όπου οι άνθρωποι αντιμετωπίζονται ως ισότιμοι εταίροι προς τους διευθυντές και τους άλλους επαγγελματίες υγείας. Αφ' ενός, αυτό σημαίνει την ικανότητα των ανθρώπων να συμμετέχουν με έναν σημαντικό τρόπο στην φροντίδα τους, και αφ' ετέρου, για τους επαγγελματίες υγειονομικής περίθαλψης σημαίνει ότι μπορούν να ακούσουν και να αποκριθούν στις ανάγκες του κοινού. Επομένως, η συμμετοχή των ασθενών και του κοινού στην παροχή φροντίδας γίνονται ζωτικής σημασίας για την βελτίωση της ποιότητας των υγειονομικών υπηρεσιών, και μπορούν να παρασχεθούν ευκαιρίες για να εξασφαλισθεί ότι οι ασθενείς είναι σε θέση να συμβάλουν σε ένα φάσμα των δραστηριοτήτων - συμπεριλαμβανομένου του προγραμματισμού των νέων υπηρεσιών, της κατάρτισης προσωπικού και της εκπαίδευσης, και της ανάπτυξης των πληροφοριών. Στους ασθενείς πρέπει να δοθούν ευκαιρίες συμμετοχής στην διαδικασία λήψης αποφάσεων επειδή είναι εμπειρογνώμονες στη λήψη της υγειονομικής περίθαλψης και επειδή θέλουν τις προτιμήσεις τους να γίνονται σεβαστές. Υπό αυτήν τη μορφή, οι ασθενείς έχουν έναν

καθοριστικό ρόλο να διαδραματίσουν στην ανάπτυξη των υγειονομικών υπηρεσιών (Sowden και συνεργάτες, 2001).

Η συμμετοχή των ασθενών ως συνεργατών και όχι απλά ως παθητικών παραληπτών στις υπηρεσίες υγείας προϋποθέτει ορισμένες ικανότητες σε όλες τις πτυχές της ανθρώπινης συμπεριφοράς. Σύμφωνα με τον Eriksson, (1997) στο γνωσιολογικό τομέα, ο ασθενής πρέπει να έχει καλή κατανόηση της ασθένειας και των άμεσων και αναμενόμενων συνεπειών της. Στον οργανικό τομέα, ο ασθενής πρέπει να διαθέτει την ικανότητα να ελέγξει τα συμπτώματα της νόσου, να αποτρέπει καταστάσεις κρίσεως, και να μπορεί να αναγνωρίζει και να χρησιμοποιεί τις κατάλληλες κοινοτικές υπηρεσίες. Στο συναισθηματικό τομέα, ο ασθενής πρέπει να έχει τη δυνατότητα να προσαρμόζεται στις γρήγορα μεταβαλλόμενες συνθήκες, να συμμορφώνεται με τις θεραπευτικές αγωγές θεραπείας και να δέχεται τους περιορισμούς στον τρόπο ζωής διατηρώντας όμως τις καθημερινές του λειτουργίες, συμπεριλαμβανομένων των κοινωνικών και να είναι ικανός να εκφράζει τα συναισθήματά του / της (Dodd και συνεργάτες, 2001). Ένας αυξανόμενος όγκος βιβλιογραφίας σχολιάζει ότι αυτές οι παράμετροι αντιπροσωπεύουν μια αλλαγή στον παραδοσιακό καθορισμό του ρόλου του ασθενή (Kim και συνεργάτες., 2004 Dodd και συνεργάτες., 2001 Goel και συνεργάτες., 2001).

Αυτή η μελέτη έδωσε επίσης έμφαση στους τρόπους με τους οποίους το εθνοιστορικό / λαογραφικό υπόβαθρο των συμμετεχόντων (νοσηλευτές και ασθενείς) επηρέασε την διαμόρφωση των αντιλήψεών τους σε σχέση με τον καρκίνο και την ποιότητα. Η μελέτη ασχολήθηκε με μια συγκεκριμένη εθνική ομάδα, αυτή των Ελληνοκυπρίων ασθενών και επομένως το εθνοιστορικό υπόβαθρο της Κύπρου είχε έναν κεντρικό ρόλο για την μελέτη. Το πολιτιστικό υπόβαθρο των συμμετεχόντων είναι μια σημαντική εκτίμηση δεδομένου ότι τώρα συμφωνείται ότι αυτό επηρεάζει τις πεποιθήσεις, τις συμπεριφορές και τη στάση μας απέναντι στην υγεία και την ασθένεια καθώς επίσης και τις αντιλήψεις για τις υπηρεσίες που μπορούμε να χρησιμοποιήσουμε (Papadopoulos, 1999). Η Leininger (1995) έχει υποστηρίξει ότι οι πολιτιστικές αξίες είναι κρίσιμα στοιχεία στην νοσηλευτική επειδή επηρεάζουν σημαντικά τους ανθρώπινους τρόπους συμπεριφοράς και δράσης. Η κατανόηση των πολιτιστικών πεποιθήσεων και των αξιών των ασθενών

γίνεται μέρος της ανάπτυξης σχεδίων προσφοράς νοσηλευτικής φροντίδας. Η Helman (1990) θεωρεί ότι το πολιτιστικό υπόβαθρό μας έχει μια σημαντική επιρροή σε πολλές πτυχές της ζωής μας, συμπεριλαμβανομένων των πεποιθήσεων, των συμπεριφορών και της στάσης μας απέναντι στην ασθένεια, τον πόνο και άλλες κακοτυχίες, οι οποίες μπορούν να έχουν επίσης σημαντικές επιπτώσεις στην υγεία και την υγειονομική περίθαλψη. Η Paradoroulos (1999) υποστηρίζει ότι οι πολιτισμοί δεν είναι ποτέ ομοιογενείς και επομένως κάποιος πρέπει πάντα να αποφεύγει τις γενικεύσεις όσον αφορά τις πεποιθήσεις και τις συμπεριφορές στην εξήγηση των λαών. Κάποιος πρέπει επομένως να αντιμετωπίζει με σκεπτικισμό τους κανόνες ενός πολιτισμού, οι οποίοι καθορίζουν πώς κάποιος πρέπει να σκεφτεί και να συμπεριφερθεί, και πώς οι άνθρωποι σκέφτονται και συμπεριφέρονται στην πραγματικότητα. Οι γενικεύσεις μπορούν επίσης να είναι επικίνδυνες, γιατί οδηγούν συχνά στην ανάπτυξη των στερεοτύπων και έπειτα στις πολιτιστικές παρανοήσεις, τις προκαταλήψεις και επίσης τη διάκριση.

Συμπεράσματα

Ο καρκίνος αποτελεί ένα προβληματικό τομέα των υπηρεσιών υγειονομικής περίθαλψης στην Κύπρο και πρόσφατα έχει προκαλέσει σημαντικές διαφωνίες μεταξύ της κυβέρνησης, των ασθενών και των συνδέσμων ασθενών με καρκίνο σχετικά με την παράδοση ποιοτικής περίθαλψης. Επιπλέον, η προσχώρηση της Κύπρου στην Ευρωπαϊκή Ένωση και η εισαγωγή ενός νέου Εθνικού Συστήματος Υγείας έχουν εισαγάγει περαιτέρω αλλαγές στην παραδοσιακή παράδοση της φροντίδας σε ογκολογικές μονάδες και αλλού, δημιουργώντας νέα πρότυπα στην φροντίδα ατόμων με καρκίνο.

Η παροχή ποιοτικής υγειονομικής φροντίδας αποτελεί προτεραιότητα στους οργανισμούς υγειονομικής περίθαλψης. Μια σημαντική πτυχή προκειμένου να επιτευχθεί η παροχή ποιοτικής περίθαλψης είναι να καθιερωθεί ένας κοινά αποδεκτός ορισμός για το τι είναι η ποιοτική περίθαλψη. Οι υφιστάμενοι ορισμοί για την ποιοτική περίθαλψη σπάνια λαμβάνουν υπόψη τις δυο πτυχές της φροντίδας, αυτή του ασθενή και αυτή του παροχέα. Αυτό το άρθρο προσπάθησε όχι μόνο να παρέχει έναν όρο

συναίνεσης για την ποιοτική νοσηλευτική φροντίδα λαμβάνοντας υπόψη και τις δύο προοπτικές αλλά και να διακρίνει αυτόν τον όρο με τον όρο της ποιότητας της ζωής.

Οι στρατηγικές για την παροχή υπηρεσιών υγείας μέσω της συμμετοχής των ασθενών και των οικογενειών τους στο σχεδιασμό και την παράδοση της φροντίδας έχουν γίνει πρωταρχικής σημασίας στα τελευταία έτη σε όλο τον κόσμο. Αυτή η μορφή αλλαγής οδηγείται από τη αυτο-ενδυνάμωση των ασθενών που προσπαθούν να λάβουν το πιο υψηλό δυνατό επίπεδο φροντίδας και τις προσπάθειες των προμηθευτών υγειονομικής περίθαλψης να μοιραστούν την ευθύνη της φροντίδας με τους ασθενείς τους. Αυτό επιτυγχάνεται από την μια κτίζοντας την ικανότητα των ασθενών να συμμετέχουν με έναν σημαντικό τρόπο στην φροντίδα τους, και από την άλλη οι επαγγελματίες υγειονομικής περίθαλψης καταδεικνύουν ότι μπορούν να ακούσουν και να αποκριθούν αποτελεσματικά στις ανάγκες και προτιμήσεις των ασθενών. Ανεξάρτητα από τη φύση της προσέγγισης που θα επιλέγει για να βελτιωθεί η παροχή νοσηλευτικής φροντίδας, το πολιτιστικό υπόβαθρο πρέπει να λαμβάνεται υπόψη. Το πολιτιστικό υπόβαθρο έχει μια σημαντική επιρροή σε πολλές πτυχές της ζωής μας, συμπεριλαμβανομένων των πεποιθήσεων, των συμπεριφορών και της στάσης μας απέναντι στην ασθένεια, τον πόνο και άλλες κακοτυχίες, οι οποίες μπορούν να έχουν σημαντικές επιπτώσεις στην υγεία και την υγειονομική μας περίθαλψη.

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