

CHAPTER 1

Orientation to the study

1.1 INTRODUCTION

Ageing is a process that begins from the moment of conception and is accompanied by the gradual impairment of body functions that may lead to death. The elderly are regarded as fragile and frail; are less active socially as well as physically as a result of organ failure and compromised immunity systems and are prone to both physical illness, including pain, and mental illness, such as dementia.

Jackson (2002a:32) describes dementia as a set of symptoms where there is a decline in memory and capacity to solve problems of daily living, performance of learned perception, motor skills and control of emotional reaction. Dementia is characterised by changing patterns of behaviour, disorientation to time, place and person, inappropriate actions and responses as well as an inability to express oneself. It affects all socio-economic groups. It is considered part of growing old, an attitude partly due to ignorance or ageism. As dementia progresses, insight may be lost so that the need for help cannot be appreciated. Patients may have a problem expressing themselves, which then leads to pain being unrecognised and therefore not managed.

Andrews and Boyle (1999:284) describe pain as "an unpleasant sensory and emotional experience arising from actual or potential tissue damage described in terms of such damage". According to McManus (2003a:1), the word pain is derived from Latin *poena* punishment, grief and from the Greek word *poine* which means penalty. Pain is subjective and is whatever individuals say it is and exists whenever they say it does. How individuals define their situation as well as the impact of the previous situation determines the experience of pain.

As people who suffer from dementia cannot articulate pain, it is often difficult to determine whether pain is physical or emotional. This poses a challenge to nurses. Nurses' opinion of pain refers to whether individuals experience any change in their behaviour or feelings. Nurses develop insight into what they see as patients' problems in terms of what they hear, what relatives say patients need and how this information is related.

This study will explore and describe nurses' opinion of pain in patients who suffer from dementia with a view to devising mechanisms for effective pain management. The researcher will use a non-experimental, qualitative, exploratory and descriptive approach that is contextual in order to capture the opinions of nurses about pain in patients suffering from dementia.

1.2 BACKGROUND TO THE STUDY

The researcher worked at the Beachcroft Nursing Home, in St. Leonards-on-Sea in East Sussex in the United Kingdom (UK) for a year. Beachcroft was a nursing home for the elderly suffering from mental illness, including dementia. The manager of the home was a registered mental health care nurse with a postgraduate degree in dementia care, who provided onsite training for all categories of nursing staff in order to improve their knowledge in dementia care.

The nursing home closed down and some of the residents as well as staff members were transferred to Grosvenor Park Nursing Home in Bexhill-on-Sea, East Sussex in the UK. Here the researcher observed a different kind of care, which was based mostly on routine physical care with very little emphasis on comprehensive care.

It is within this nursing home that the researcher observed elderly patients who were restless and often labelled as being "difficult". The researcher decided to conduct a study to determine whether pain was not the origin of the restlessness or "difficult" behaviour and if the experienced pain by the elderly should not be investigated. It is a challenge if patients have lost the power of speech due to dementia and cannot articulate their pain. Stein and Ferrell (1996:575) note that regardless of the setting, the occurrence of sensory impairments, dementia and disability make assessment and management a challenge.

Briggs (2002:23) points out that there are misconceptions about pain in the elderly among the nurses, including that pain is a natural outcome of growing old or that pain decreases with age. These misconceptions need to be discussed and corrected to improve pain management. According to Briggs (2002:21), the prevalence of pain in clients with dementia can be as high as 85% and pain in this patient group is under-recognised and therefore under-treated. As patients suffering from dementia cannot verbalise their discomfort, it is difficult to determine whether change in behaviour is due to a physical or emotional cause.

With progression, the need for help by relatives, friends and other helpers including nurses, may not be appreciated. Attempts to help patients suffering from dementia, may cause anger and frustration for both client and nurse. Staff members may feel helpless because they cannot detect the cause of pain or rely on their intuition to assume that the patients is/is not experiencing pain (Jackson 2002b:44). As the condition worsens, clients eventually become incapable of managing their own affairs, therefore a power of attorney is appointed (a third party) to manage their affairs. The British Mental Health Act of 1983 makes provision for guardianship by which patients suffering from mental disorders may be required to reside at a specific place, attend specific places for treatment and specific places for occupation. An "Enduring Power of Attorney" is appointed when the patient still has a sound mind. Once the individual becomes impaired the only recourse is to the Court of Protection in the UK (Pathy 1998:1050).

Burgess (2003:18) states that the number of people suffering from dementia increases with age and doubles every five to six years in the UK. Currently it is estimated that 18 500 people under the age of 65 in the UK suffer from dementia. Table 1.1 represents the prevalence of dementia in the UK.

Table 1.1 Prevalence of dementia in the United Kingdom

AGE (YEARS)	PREVALENCE
40-64	1:1 000
65-69	1:50
70-80	1:20
80+	1:5

Source: Alzheimer's Society (2004a:14)

Table 1.1 indicates that the ratio of dementia sufferers increases from 1:1000 in the age group 40-64 years to 1:50 between 65-69, 1:20 between 70-80 and 1:5 in 80+. According to this table, it is clear that the prevalence of dementia increases with age in the UK.

According to Ford and Heath (1996:162), the prevalence of dementia varies from country to country. For example, in the UK and the United States of America, Alzheimer's disease is common, while vascular dementia is more common in Japan. In the UK the prevalence of dementia in the total population is less than 0,1% for the age group 45-60 years, an increase of 2% for the age group 65-70 years and 5% for the age group 70-80 years. The figure is nearer 20% for patients over 80 years of age. This tendency is reflected in table 1.2.

Table 1.2 Prevalence of dementia worldwide

AGE GROUP	PREVALENCE RATE %
65-79	1,4
70-74	2,8
75-79	5,6
80-84	11,1
85+	23,6

Source: Alzheimer's Society (2004a:14)

From table 1.2 it is evident that, as with the figures given in table 1.1 of the prevalence of dementia in the UK, the same progressive ratio is found globally, namely that as age increase, the prevalence rate of dementia increases. It is also significant that the

prevalence rate increases dramatically from age 80-85 years.

One can thus expect that the number of people who suffer from dementia globally is expected to increase steadily over the next twenty-five years Alzheimer's Society (2004a:14). Figure 1.1 indicates the prevalence of dementia worldwide.

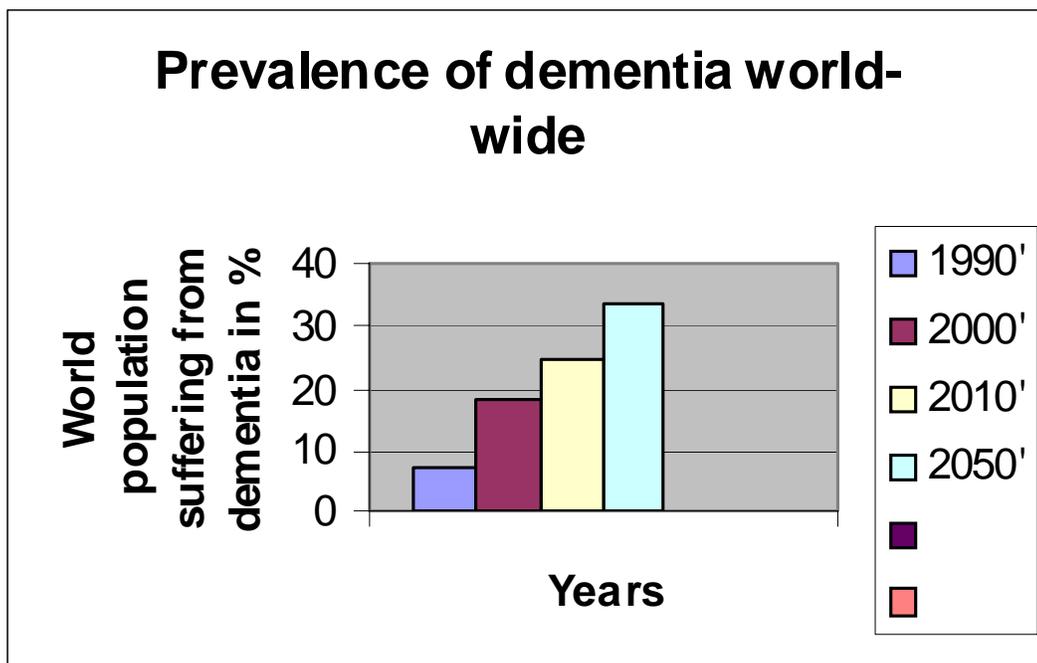


Figure 1.1
Prevalence of dementia worldwide

Source: Alzheimer's Society (2004a:14)

From figure 1.1 it can be deduced that in 1990 7,4% people suffered from dementia. Currently nearly 18% of the elderly population suffers from dementia and it is estimated that by 2015, 34% of the elderly population will suffer from dementia (Alzheimer's Society 2004a:14). From this figure and the tables provided above (see table 1.1 and 1.2) it is evident that health care services and especially those caring for the aged, need to be more aware of pain management in patients suffering from dementia because pain is often also associated with ageing.

1.3 PROBLEM STATEMENT

According to McManus (2003b:502), pain is “an unpleasant sensation, which hinders and leads to reduced quality of life”. Thus, patients who are experienced as being “difficult”, aggressive, depressed or restless may possibly experience physical symptoms of pain which are often overlooked by nurses. Patients with dementia experience pain as a result of other co- morbidities such as arthritis, but may be undiagnosed and therefore under-treated due to change in their behaviour. Inability to express pain causes concern to the nurse who provides care to the patient. Although some consequences of ineffective pain management have been evaluated, the question of nurses’ opinions of pain experience in patients who suffer from dementia has, according to the extensive literature search done by the researcher, not been investigated.

1.4 PURPOSE OF THE STUDY

The purpose of this study is to describe and explore nurses’ opinion of pain in patients suffering from dementia.

The researcher will conduct the study in three phases, namely conceptual, narrative and interpretative.

1.4.1 Conceptual phase

The conceptual phase involves formulating the research question and objectives for the study in order to examine the phenomenon under study. A literature review will be conducted to familiarise the researcher with the concept and existing knowledge on the subject. The researcher will employ bracketing to lay aside any preconceived ideas about the phenomenon under study (see description in chapter 3, section 3.3).

1.4.2 Narrative phase

This phase involves planning and selecting the research design and methodology. The researcher will be the instrument used to collect narrative data from the participants. The

researcher will use focus group interviews to collect data. Non-purposive probability sampling will be used and a pilot study conducted (see description in chapter 3, section 3.4).

1.4.3 Interpretative phase

This phase involves data analysis and interpretation. Data analysis will commence after the interviews have been conducted. After interpretation and on completion of the study, the researcher will validate the findings with reference to the literature reviewed.

1.5 RESEARCH QUESTIONS

For the purposes of the study, the following research questions will guide the researcher:

- What is nurses' opinion of pain in patients who suffer from dementia?
- How do nurses assess pain in patients who suffer from dementia?
- How do nurses deal with pain in patients who suffer from dementia?
- What competencies do nurses feel they need to manage pain in patients who suffer from dementia?

1.6 OBJECTIVES OF THE STUDY

The study aims to explore and describe

- nurses' experiences in interpreting pain in patients suffering from dementia
- strategies used by nurses in assessing pain in patients who suffer from dementia
- the way in which nurses manage pain in patients suffering from dementia
- mechanisms for pain management in patients suffering from dementia

1.7 SIGNIFICANCE OF THE STUDY

According to various researchers (Arnst, Licking & Barrett 1999:1-5; McManus 2003a:1-6; McManus, 2003b:1223-1232), nurses who work in nursing homes where the aged are

cared for often do not perceive the behaviour of the elderly as due to experiencing of pain. The researcher therefore argue that nurses who work in the homes for the elderly, need the collaboration of other nurses from the hospital setting as well as the community to interpret pain in patients in this category to provide care, using a multi-disciplinary approach. It is envisaged that the results of this study could influence the following:

- nurses' opinion of pain in patients who suffer from dementia
- the strategies used to assess pain in patients who suffer from dementia
- policy on management of pain in patients who suffer from dementia
- the adequate management of pain in patients who suffer from dementia.

1.8 DEFINITIONS OF TERMS USED IN THE STUDY

The following terms are used in this study as defined below.

- **Dementia**

Collins English Dictionary (2005:420) defines dementia as “a state of serious emotional and mental deterioration, of organic or functional origin”. Fares (1997:49) describes dementia as a set of symptoms characterised by a decline in memory, capacity to solve problems of daily living, performance of learned perception and motor skills and control of emotions.

In this study, *dementia* refers to a collection of symptoms characterised by loss of memory, inability to express pain, make decisions on problems of daily living, and control emotions.

- **Nurse**

Collins English Dictionary (2005:1073) defines a nurse as “a person, usually a woman, who is trained to tend the sick, injured and infirm”. The Nursing and Midwife Council of the UK (NMC) defines a nurse as “someone who is registered to practise the nursing profession” (The Nurses, Midwives and Health visit Act 1979: Chapter 36) of the UK.

In this study, a *nurse* is viewed as a professionally trained person (registered nurses as well as registered mental health care nurses) who is registered with the statutory body to practise nursing of the aged population including caring for patients who suffer from dementia.

- **Pain**

Collins English Dictionary (2005:1121) defines pain as “the sensation of acute physical hurt caused by injury or illness, etc; emotional suffering or mental distress”. Andrews and Boyle (1999:284) define pain as an “unpleasant sensory and emotional experience arising from actual or potential tissue damage.”

For the purpose of this study, *pain* refers to an unpleasant sensation experienced as a result of physical hurt or discomfort caused by injury or illness, emotional suffering or mental distress.

- **Patient**

Collins English Dictionary (2005:1143) defines a patient as “a person who is receiving medical care”. For the purpose of this study, *patient* means an aged person who suffers from dementia and is unable to verbalise or express pain experience.

- **Opinion**

Collins English Dictionary (2005:1095) defines opinion as “judgement or belief not founded on certainty or proof”. In this study, *opinion* means the different views of nurses who care for patients with dementia to interpret their behaviour as well as pain, based on their beliefs and judgement.

1.9 ASSUMPTIONS

According to Burns and Grove (2003:41), assumptions are “statements believed to be true

without verification”. Assumptions are embedded in the researcher’s thinking and behaviour. Uncovering them requires introspection and a strong knowledge base in a research area. They influence the development and implementation of the research process as well as the logic of the study. In research studies assumptions are embedded in the philosophical base of the study, study design and interpretation of findings. Theories and instruments are developed on the basis of assumptions and are considered part and parcel of the research process in qualitative studies.”

For the purpose of this study, ontological assumptions apply. Burns and Grove (2003:41) describe ontological assumptions as “assumptions about human nature, society, the nature of history, the status of mental entities, observable and material phenomena, and causality and intentionality in human action and behaviour”.

This study is based on the following assumptions:

- Nurses lack knowledge about elderly patients’ pain.
- Elderly patients with less discomfort would be less agitated and confused.
- Pain transmission is shown in the elderly but pain intensity does not diminish.
- Elderly patients may be reluctant to report pain, viewing it as a sign of ageing.

1.10 RESEARCH DESIGN

Parahoo (1997:142) describes a research design as “a plan to describe how, when and where data are to be collected and analysed”. In this study, the researcher will use a non-experimental research design, adopting a qualitative research approach that is exploratory, descriptive and contextual.

1.10.1 Qualitative approach

A qualitative approach will enable the researcher to obtain detailed information from nurses who care for patients suffering from dementia on how they view pain and their experience in interpreting pain.

1.10.2 Population

Parahoo (1997:218) defines population as “the total number of units from which data can be collected”, such as individuals, events or organisations. Burns and Grove (2003:213) add that population is all the elements that meet the criteria for inclusion in a study. In this study the population will consist of the following:

- Registered general nurses and registered mental health care nurses who care for patients suffering from dementia in a specific nursing home caring for the elderly with dementia and mental illnesses.
- Trained health care assistants employed in the nursing home for patients suffering from dementia.
- Home managers who are registered nurses from the nursing home where patients are cared for who suffer from dementia.

1.10.3 Sampling

Burns and Grove (2003:31) describe sampling as “a process of selecting people, events or other elements for conducting a study”. Polit and Hungler (2002:234) add that in sampling a portion that represents the whole population is selected.

In this study the researcher will use purposive non-probability sampling to select participants. Burns and Grove (2003:255) describe purposive sampling as a sampling method whereby researchers use their own judgment in selecting the participants to include in the study. Polit, Beck and Hungler (2001:467) describe non-probability sampling as “the selection of sampling units from a population using non-random procedures such as convenience, purposive and quota sampling”.

This researcher considers this method appropriate to obtain the desired information based on expertise and experience from nurses who care for patients who suffer from dementia (see chapter 3).

1.10.4 Context (setting)

The study will be conducted at Grosvenor Park Nursing Home in Bexhill-on-sea, East Sussex in the UK. It is a nursing home that provides non-comprehensive (hotel-type service) health care but has accommodated patients who suffer from dementia.

1.10.5 Research instrument

Narrative data will be collected from participants using a focus group discussion (see annexure D).

1.10.6 Data collection

In qualitative research the researcher is the primary data collection tool. The researcher needs to lay aside any preconceived ideas or beliefs so that they do not interfere with or influence the participants' experience (Parahoo 1997:296).

1.11 DATA ANALYSIS

According to Holloway and Wheeler (2002:236), data analysis in qualitative research is not a linear process. Qualitative researchers collect and analyse data simultaneously. In this study data will be analysed as it is collected and also after collection. The four techniques of trustworthiness include: credibility, dependability, conformability and transferability will ensure rigour (see chapter 3). Table 1.3 provides a summary to illustrate the strategies to ensure trustworthiness in this research.

Table 1.3 Strategies for trustworthiness

STRATEGY	CRITERIA	APPLICATION BY RESEARCHER
Trustworthiness	Reflexivity	Bracketing and intuiting in each phase of the research process
	Prolonged engagement	The researcher has worked in the establishment since 2001 and has a trusting relationship with the participants involved in the study.

Peer debriefing	Focus group interview and data analysis by an independent external coder with a master's degree.
Authority of researcher	Member checking with participants as well as other members more experienced in dementia care such as colleagues from other nursing homes.
Referential adequacy	Involved with the phenomenon since 2001 Registered nurse for 23 years Pre-exercise interview and analytical skills
Interview technique	Pilot study (pre-exercise) to improve interviewing skills Conducting the research project's interview competently
Purposeful sample	Sample to include participants from different cultural backgrounds Sample to comprise nurses with varying experiences
Dense description	Data on participants, research context and the setting provided
Stepwise replication	Data coded and decoded after collection Member checks of codes, themes, categories and sub-categories Supervisors will compare and examine the data
Inquiry audit	The two research supervisors will audit the research project
Audit trail	Researcher will audit all the phases of research with the help of the research supervisors The inquiry trail will contribute to confirmability and dependability
Confirmability occurs with	Credibility, transferability
Credibility, transferability	Conclusions and interpretations will be derived directly from the data obtained

(Lincoln & Guba)

1.12 ETHICAL CONSIDERATIONS

Ethical considerations are the moral standards that the researcher should adhere to throughout the study. Accordingly, the principles of protection from harm, voluntary consent and participation and confidentiality will be upheld in this study (Holloway 1996:55). Ethical considerations are an important aspect of this study. Engaging in research brings with it the personal and professional responsibility to ensure that the study is both ethically and morally sound. Ethical considerations will be discussed in detail in chapter 3.

1.13 SCOPE AND LIMITATIONS OF THE STUDY

Burns and Grove (2003:42) describe limitations as methodological and theoretical restrictions in a study that may decrease the generalisability of the findings.

1.13.1 Methodological limitations

Methodological limitations can limit the credibility of the findings and restrict the population to which the findings can be generalised (Burns & Grove 2003:42). This study has the following limitations:

- The sample size is probably not representative of the population under study due to the small number of nurses working in the nursing home.
- The instrument used for data collection may have limited credibility because it has not been tested before.
- The restrictions in the study may limit the credibility of the findings and the population to which the findings can be transferred.
- There is a need for more studies to be done in this area to improve the transferability of the findings and to establish trustworthiness of the data collection instrument.

1.13.2 Theoretical limitations

The researcher recognises the possibility of weakness in the conceptual as well as operational definitions that may restrict the abstract generalisation of the findings.

1.14 OUTLINE OF THE STUDY

Chapter 1 introduced the study.

Chapter 2 discusses the literature review conducted by the researcher.

Chapter 3 describes the research design and methodology.

Chapter 4 presents the data analysis and findings.

Chapter 5 concludes the study, discusses its limitations and makes recommendations for future research.

1.15 CONCLUSION

This chapter outlined the research problem under study, the rationale for the study, the research questions and the assumptions. The researcher chose a qualitative approach that is explorative, descriptive and contextual to concentrate on the opinions of nurses (affective aspect) of pain in the elderly who suffers from dementia. The population, sampling, data collection instrument as well as the strategies for data analysis and ensuring rigour were also described.

Chapter 2 discusses the literature review undertaken by the researcher.