

CHAPTER 4

Data analysis

4.1 INTRODUCTION

This chapter discusses the data analysis and findings according to the participants' opinion of pain in patients who suffer from dementia. In addition, the researcher discusses in this chapter the meeting of the patients needs, the inability to meet their needs, caring and safe environment, opinion of pain, pain assessment, pain management and support services available for patients with dementia. These findings emerged from the literature through bracketing and intuiting and the focus group interview (see chapters 2 and 3).

4.2 PARTICIPANTS' BIOGRAPHICAL DATA

The biographical data reflected the participants' personal details. Although this is a qualitative study, quantitative data was obtained from the participants that are reflected in the following figures and table. This was necessary to establish the level of expertise as well as the experience of the work in the nurses.

- **Age**

In the following figure (figure 4.1) the age of the participants are reflected.

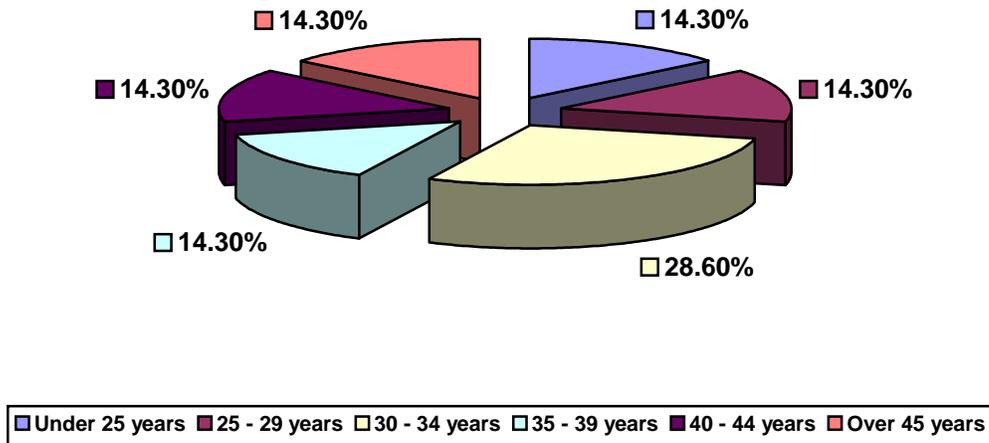


Figure 4.1
Age of the participants (N=7)

From figure 4.1 it is evident that the 7 participants represented quite a heterogeneous group with regard to age. One of the participants, was under 25, 1 was 25, 2 were 30-34, 1 was 35-39, 1 was 40-44 and 1 was over 45.

- **Gender**

All seven participants were female. It is significant to note that males are not often found to work in the context as described for this research.

- Professional status

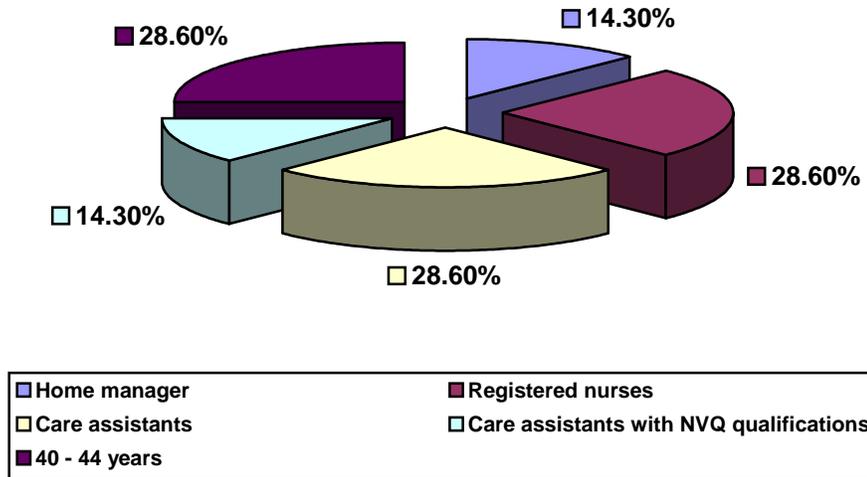


Figure 4.2
Professional status of participants (N=7)

In figure 4.2 the professional status of the participants are reflected. Of the 7 participants, 1 was a home manager with a degree in social sciences, 2 were registered nurses, 2 were care assistants with NVQ qualifications and 2 were care assistants.

- Experience

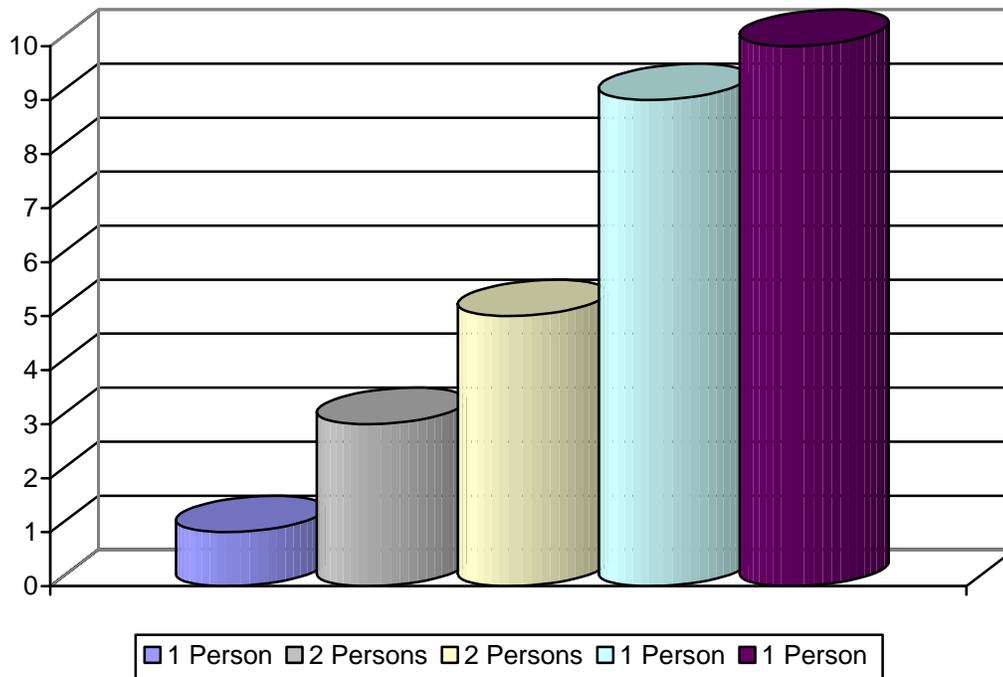


Figure 4.3
Experience in years

In figure 4.3 the experience in years of the participants are reflected. From this figure it is evident that 1 had worked less than a year, 2 had 2-3 years', 2 had 4-5 years, 1 had 8-9 and 1 had over 10 years' experience.

- Average hours per week

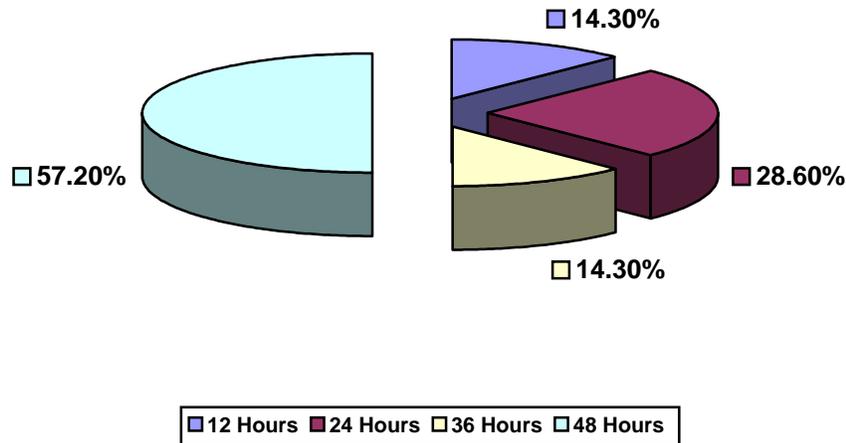


Figure 4.4
Average hours work per week

In figure 4.4 the average hours worked per week by the participants are reflected. Of the participants, 1 worked up to 12 hours, 2 worked 24 hours, 1 worked 36 hours and 4 worked up to 48 hours per week.

Table 4.1 Participants' biographical data

| AGE RANGE | QUALIFICATIONS | LENGTH OF EXPERIENCE | AVERAGE HOURS PER WEEK | NATIONALITY |
|-----------|-----------------------------|----------------------|------------------------|----------------|
| 24 | C/A+ NVQ | 5 years | 24 | British |
| 25 | RGN | 2 years | 42 | Indian |
| 34 | C/A+ NVQ | 4 years | 36 | El Salvadorean |
| 34 | C/A | 4 years | 48 | Zimbabwean |
| 39 | RGN | 3 years | 48 | South African |
| 44 | C/A | 10 years | 24 | British |
| 46 | Social worker(home manager) | 9 years | 40 | British |

Table 4.1 depicts a summary of the participants' ages, qualifications, length of experience, nationality and average hours worked per week. Some of the participants were part-time and full-time workers.

From table 4.1 it is evident that the average age of the participants are 35.14 years of age. This is an indication that this selected group is experienced and mature.

All the participants had post basic qualifications, 6 of the participants had qualifications in nursing, while the manager was a social worker.

A total of 37 years of experience between the seven participants were found, with an average of 5,28 years of working in elderly care. This is quite significant as this indicates a group of people who is mature and has experience in working with the elderly.

The average work hours that each individual worked is also reflected in table 4.1. It is significant that between the 7 participants an average of 37.42 hours per week was worked. Only 2 participants worked more than 48 hours per week.

From the 7 participants, only 3 were British, while 1 was an Indian, 1 South African, 1 a Zimbabwean and 1 from El Salvadore. This is an indication that a heterogeneous group was present.

4.3 DISCUSSION OF RESULTS

In this section the qualitative data is reflected. The researcher analysed the data manually in order to organise, provide structure to and elicit meaning from the data (Polit et al 2001:381). The researcher created categories and codes from the data obtained from the focus group discussion. Themes emerged after examining the categories and codes.

The following themes from the focus group discussion on the participants' opinion of pain in patients who suffer from dementia were identified:

- Initial emotional reaction when caring for patients who suffer from dementia
- Challenges in meeting the needs of patients suffering from pain
- Emotional reaction when unable to meet the patients' needs
- Provision of a safe and caring environment to alleviate pain
- Nurses' opinion of pain
- Assessment of pain
- Pain management
- Available support systems to alleviate pain

The categories and coding system, from the most general to the most specific level, were as follows:

- Level 1: Themes
- Level 2: Categories
- Level 3: Codes
- Level 4: Text (data) units (quoted participants' responses)

The themes were discussed with reference to the literature as the researcher attempted to describe the opinions of nurses of pain suffered by patients with dementia.

The themes aided the researcher to explore and describe

- the opinions of nurses in caring for patients who suffer from dementia
- the experience of nurses in interpreting pain in patients who suffer from dementia
- the nurses' management of pain
- strategies used by nurses to assess pain in patients who suffer from dementia.

4.4 INITIAL EMOTIONAL REACTION WHEN CARING FOR PATIENTS WITH DEMENTIA

The participants' initial emotional reaction on first encountering patients suffering from dementia included fear, feeling sorry for them and being scared. Their subsequent emotion

was feeling comfortable with themselves and among the patients.

4.4.1 Fear

Collins English Dictionary (2005:563) defines fear as “a feeling of distress, apprehension, or alarm caused by impending danger; concern, anxiety”. Sternberg (1995:580) states that fear serves as a protective mechanism because it motivates people to avoid or flee from things that might harm them. The nurses’ fears were engendered by uncertainty about caring for the patients and fear of being harmed by the patients. These emotions were reflected in the following responses (see table 4.2):

Table 4.2 Fear

| SUBCATEGORY | MEANING UNIT |
|----------------------------------|--|
| 4.4.1 Fear of the unknown (F112) | I became afraid... I didn't know if I will be able to give them the care. (A1) ...I was terrified, I did not know if I would cope. (A1) |
| Fear of being harmed (F116) | When she held my hand I was really frightened, I thought she was going to hurt me. (A1) |

4.4.2 Sympathy

Collins English Dictionary (2005:1562) defines sympathy as “the sharing of another’s emotions, esp. of sorrow or anguish; pity; compassion”. The nurses sympathised with the family for feeling helpless and their inability to interpret the patient’s behaviour (see table 4.3).

Table 4.3 Sympathy

| SUBCATEGORY | MEANING UNITS |
|---------------------------------------|--|
| 4.4.2 Sympathising with family (F111) | I used to watch my mother cry because she did not know what to do. (C4) I felt sorry for them, they were old ... and they were confused. (A2) |
| Sympathising with the patients (F115) | I just felt so sorry for them. (C4) |
| (F112) | I felt sorry...I didn't know if I would cope looking after them. (A1) |

4.5 CHALLENGES IN MEETING PATIENTS NEEDS

Patients' needs refer to basic needs according to Maslow's hierarchy of needs, including need for shelter, food, to be treated with respect and dignity, as well as love. Although patients with dementia are unable to express their needs, nurses are patients' advocates ensuring that patients' needs are met. To ensure that the patients' needs are met, nurses need to assess the needs, involve the family, and observe body language. Nursing homes and institution should keep the same staff for a long time (see table 4.4).

Table 4.4 Assessment of needs

| SUBCATEGORY | MEANING UNITS |
|---------------------------|--|
| 4.5.1 Assess needs (F114) | When the patient used to go to the toilet at certain times of the day, you get to know it, because her behaviour will show. (B1) |
| F117 | Sometimes they cry. (B2) |
| F113 | It depends ... like when they are happy they smile. (B1) |

4.5.1 Family background

The family is the patient's primary support system. They spend most of the time with the patient before and during the different stages of dementia. The family observe salient changes that take place and also learn how to interpret the patient's behaviour, hence the family's involvement and contribution is significant to the nursing staff. According to Forbat

(2004:2), knowledge of the family background enables nurses to develop insight into how family members manage with difficulties and how they negotiate and access services. According to the Alzheimer's Society (2004a:14), providing staff with personal background such as likes, dislikes, family, employment as well as interests provides a fuller picture of the person and helps nurses to plan activities and day-to-day caring of the patient. (see table 4.5).

Table 4.5 Family background

| Subcategory | Meaning units |
|-----------------------------------|--|
| 4.5.2.1 family involvement (F111) | The family knows the patient better ... because they know what makes him happy and what upsets him. (B1) |
| (F116) | It helps to know their family background because sometimes the things that they come out with don't make sense. (G4) |
| (F113) | The family will be able to tell you why they behave that way. (B1) |

4.5.2 Non-verbal behaviour

Non-verbal communication is a more accurate form of communication and 90% of messages are conveyed in this form. Patients who suffer from dementia cannot express or verbalise their feelings so an ability to interpret their body language or behaviour enables nurses to meet the patients' needs. According to Stewart (2004:1), caregivers need to watch out for body language. Its signs include pacing, withdrawing from others, shaking fists and backing away from others (see table 4.6).

Table 4.6 Patients' non-verbal behaviour

| SUBCATEGORY | MEANING UNITS |
|--------------------------------------|--|
| 4.5.3.1 Non-verbal behaviour (F 112) | They can be quiet ... or sometimes get very aggressive. (B3) |
| (F113) | If they have a smile on their face it means they are satisfied. (B1) |
| (F114) | Do continuous assessment and also observe their behaviour. (B1) |

4.5.3 Staff retention

Staff members that stay in one unit for a long time tend to know the patients better and are able to detect any change in patients' behavior. The patients also see them as family members and relate well to the nurses. This, in turn, improves the standard of care in the unit. According to Socia (2003), the more time spent with cognitively impaired older adults, the more opportunity nurses have to learn particular traits. Recognising change is the first step in determining the presence of pain in elderly patients (see table 4.7).

Table 4.7 Staff retention

| Subcategory | Meaning units |
|--------------------------------|---|
| 4.5.4.1 Staff retention (F111) | Keep same staff members in the same unit ... they learn to understand patients better. (B4) |
| (F116) | If nurses stay in the same unit for a long time they are like family to the patients. (D1) |

4.6 EMOTIONAL REACTION WHEN UNABLE TO MEET THE PATIENTS' NEEDS

Meeting a patient's needs is a primary goal for nurses who care for patients with dementia especially as they cannot express their needs. The inability to interpret patient behaviour or meet their needs may lead to emotional reactions for both patients and nurses. Nurses' reactions include frustration and guilt. Patients' reactions include aggression and frustration (see table 4.8).

4.6.1 Frustration

According to Small (2004), patients become agitated out of frustration or conversation becomes too complex or perhaps they forget the content of the discussion. Marcelle (2002) states that patients may be frustrated with getting old and losing control. Coyne, Polenza and Berbig (2004) emphasise that caregivers may become frustrated and helpless leading to abusive behaviour: "The staff reported bruises on Joyce's arms which

were painful to touch. When they confronted Jim in a firm but not rejecting manner, he admitted that at times he became so frustrated with Joyce that he would grab her and shake her. It also became clear that as his wife illness got worse, his anger and frustration grew, farther increasing the likelihood of abuse.”

Table 4.8 Frustration

| Subcategory | Meaning units |
|--------------------------------------|---|
| 4.6.1.1 Frustration of nurses (F111) | I used to be so frustrated when I could not understand Mrs S. (A1) |
| (F114) | You get frustrated when you don't know what they want. (B1) |
| (F117) | It's sometimes just frustrating to be here. (B1) |
| Frustration of patients (F113) | You can see ... when you don't understand them, they get frustrated and angry. (C1) |
| (F115) | Mrs S looked so helpless ... (B3) |

4.6.2 Aggressive behaviour

According to Mental Help Health Foundation (2004:6), aggression is action, i.e. attacking someone or a group. It is intended to harm someone. It can be a verbal attack -- insults, threats, sarcasm, or attributing nasty motives to them – or a physical punishment or restriction. Pariot (2004) states that aggression is a hostile action directed towards self, others or objects. The Alzheimer’s Society (2003:7) adds that aggressive behaviour may be due to overstimulation, physical discomfort, unfamiliar surroundings or persons, complicated tasks and frustrating interactions. Dash and Villemarett-Pittman (2005) assert that aggressive behaviour might be the only way the patient who suffers from dementia can show anger. Patients’ aggressive behaviour is often caused by being misunderstood (see table 4.9).

Table 4.9 Aggression

| Subcategory | Meaning unit |
|---------------------------|---|
| 4.6.2.1 Aggression (F114) | They lash out for no reason at all. (E1) |
| (F115) | He was fighting another patient, kicking and punching him. (A1) |
| (F113) | He was chasing me, his eyes were protruding ... I was really scared. (D2) |

4.6.3 Guilt

According to La Rowe (2005:2), the role of the caregiver at home is usually followed by varying degrees of guilt. This is usually guilt that the family could have done more, should have known better or should have done things differently. Ferry (2005:1) points out that for many caregivers long-term promises of never placing one another in a nursing home were made and compromising the promises produces guilt on the caregiver’s part. According to Kerwin (2004), caregivers “often experience feelings of guilt, believing they are not doing enough to help. Spouses and adult children feel grief and loss, not unlike a death in the family - except that instead of being sudden, it’s spread out over years.”

Table 4.10 Guilt

| Subcategory | Meaning units |
|----------------------|---|
| 4.6.3.1 Guilt (F112) | When you don’t know what they want, you feel so bad, you um ... blame yourself, to the extent of feeling guilty. (C3) |
| (F111) | When the family leaves them here, they feel guilty because they feel they have failed them. (H4) |
| (F114) | I feel so... bad, really awful. (C3) |

4.7 PROVISION OF A CARING AND SAFE ENVIRONMENT

A safe and caring environment is an environment conducive to recovery. Patients who suffer from dementia deserve the optimum care nurses can provide, especially due to their inability to express themselves. Warner (2004) maintains that to ensure physical safety means that locks are important barriers necessary to prevent the patient leaving the safety

of home. According to Weiner (2004), individuals with dementia need assistance with activities of daily living whether at home or in care settings. This involves creating an environment that is safe, sustains the dignity of the person and optimises opportunities for independent decision making (see table 4.11).

Table 4.11 Safe and caring environment

| SUBCATEGORY | MEANING UNITS |
|--|--|
| 4.7.1 Physical safety (F112) (F114) | We need to ensure that we remove anything that will cause injury, especially wires that are lying around. (F1) Allow them to wander around under supervision. (F3) |
| 4.7.2 Emotional safety (F116) (F112) (F113) | In the dementia unit, we had codes for the doors, sometimes locked doors. (F2) We need to make them feel special and treat them like humans, not as people who suffer from dementia. (A5) They need our love; we really need to love them. (F4) Make them comfortable. (G1) |

4.8 NURSES' OPINION ON PAIN

Collins English Dictionary (2005:1095) defines opinion as “judgment or belief not founded on certainty or proof; evaluation, impression, or estimation of the value or worth of a person or thing”. Nurses’ opinion of pain depends on their observation, interpretation of patients’ behaviour, physical symptoms as well as self-report. An individual’s opinion of pain may have both personal experience and cultural connotation. Kovach, Griffie, Muchka, Noonan and Weissman (2004) found the most cited behaviours to indicate discomfort were facial grimacing, restless body movement, change in behaviour, moaning and tense muscles. Observation of vital signs such as temperature, pulse and blood pressure, enable nurses to detect the possibility of the presence of pain. When the patient experiences pain the vital signs are elevated (see table 4.12).

Table 4.12 Observation of vital signs

| SUBCATEGORY | MEANING UNITS |
|---------------------------------------|---|
| 4.8.1.1 Monitoring vital signs (F114) | I mean the patient's vital signs will be elevated ... I don't know, I guess it is just a physiological reaction. (B1) |
| (F117) | Check if the patient does not need things like food, or they might be thirsty. If not, it might be they are in pain. (G1) |

4.8.1 Patients' behaviour

Staff retention enables nurses to interpret patients' behavior because the staff who work in a unit longer tend to know the patients better. A deviation from normal behaviour causes concern to nurses. Patients who suffer from dementia may become very quiet or aggressive (see table 4.13).

Table 4.13 Non-verbal behaviour

| SUBCATEGORY | MEANING UNITS |
|-------------------------------------|--|
| 4.8.3.1 Non-verbal behaviour (F113) | They can be very quiet ... sometimes they become aggressive. (B3) |
| (F112) | He was chasing me, his eyes were protruding. I was really scared. (D2) |
| (F114) | He lashed out for no reason at all. (E1) |

4.8.2 Physical symptoms

According to Weissman, Griffie and Muschka (2004), common signs of pain displayed by people with late stage dementia include increased agitation, fidgeting or repetitive movements, withdrawal, changes in sleep pattern, falling, increased pulse rate and blood pressure, and sweating. People react differently to pain. Symptoms of the presence of pain include crying, screaming, shutting the eyes (see table 4.14).

Table 4.14 Physical symptoms

| SUBCATEGORY | MEANING UNITS |
|----------------------------------|---|
| 4.8.3.2 Physical symptoms (F117) | Sometimes they cry. (B2) |
| (F111) | ... like screaming, being very quiet or being aggressive. (B3) |
| (F113) | They tell you that they are in pain, but not always. You have to figure out. (E3) |
| (F112) | They draw the knees up when they have tummy ache or hold the affected part, like Mrs S who likes to hold the side of the face. (E3) |

4.9 ASSESSMENT OF PAIN

According to Schempp (2004), to assess pain the nurse needs to push gently on an area and ask if it hurts, check changes in facial expression, such as grimacing, and behavioural changes, such as restlessness, agitation, vocalisation or fast pulse rate. Agarwal (2004) asserts that pain assessment includes location of pain, type, intensity, frequency as well as type. King (2004) adds that tools used for pain assessment to administer such as asking the patient to score the patient on a 0-10 scale or on a simple descriptive scale (“no pain” to “worst possible pain”).

Strategies to assess pain include observation, non-verbal behaviour as well as involving the family.

4.9.1 Observation

Table 4.15 Observation

| SUBCATEGORY | MEANING UNITS |
|---|---|
| 4.9.1.1 Monitoring vital signs (F114) | I mean vital signs will be elevated. I don’ know ... I think it’s just a physiological reaction. (B2) |
| 4.9.1.2 Observe their non-verbal behaviour (F111) | They just shut their eyes and do not say anything. (G2) |
| | Mrs S would hold the side of her face and looked so helpless. (B3) |
| | Each time she went to the toilet she would scream. (B2) |

4.9.2 Family involvement

According to Kelley and Specht (2004), family involvement is an intervention to facilitate quality care for patients who suffer from dementia and assist the family to find meaningful and satisfactory care-giving roles despite the setting. Patients with dementia are unable to verbalise their needs, and at times nurses find it challenging to assess pain or interpret behaviour.

Involving the family enables nurses to provide the appropriate care, because the family knows the patient better and can tell when there is change in behaviour. LaBrake (2004) is of the opinion that involving the family fosters communication and collaboration between staff members and family. Socia (2003) adds that patients' family members and friends are often attuned to changes in their loved ones' behaviour, and their input can also assist nurses in assessing pain (see table 4.16).

Table 4.16 Family involvement

| SUBCATEGORY | MEANING UNITS |
|-----------------------------------|--|
| 4.9.2.1 Family involvement (F111) | The family knows the patient better ... they know what makes him happy and what upsets him. (B3) |
| (F116) | Involve the family because sometimes the things they come out with don't make sense. (G4) |

4.10 PAIN MANAGEMENT

According to Burke (2004), management of pain depends on the nature, source and intensity of pain. Non-opioid and opioid analgesics are commonly used to treat pain. Non-opioid analgesics such as Tylenol and non-steroidal anti-inflammatory drugs (NSAIDs) are useful for relief of mild to moderate pain, including arthritic pain.

Management of pain ranges from conventional to alternative medicine (see table 4.17).

Table 4.17 Pain management

| SUBCATEGORY | MEANING UNITS |
|----------------------------------|--|
| 4.16.1 Pain management (F113) | It depends on the level of the pain. For mild pain, make the patient comfortable. (H1) |
| (F112) | Give analgesia as prescribed by the doctor. (H3) |
| | Give a patient a massage or aromatherapy. (H2) |
| (F111) | Involve the family because they know effective treatment for the patient. (B3) |

4.11 AVAILABLE SUPPORT SYSTEMS

According to the Mental Health Foundation (2004:6), services are available to assist the family or carers of patients that suffer from dementia, by providing emotional support and opportunities for families and carers to come together and share views and concerns regarding their loved ones, learn practical information and talk to people who can relate to their frustrations. Gallergher-Thompson (cited in Brandt 2004) states that their programme focuses on increasing self-efficacy by teaching caregivers to manage their time better, becoming more assertive in asking for help from others, channelling their thoughts more positively and preparing for the future.

Dunhoff (2004) refers to the Pitt study on family members who provide care for loved ones with dementia that found that most caregivers need more support before than after the patient's death. Table 4.18 represents support systems available to families.

Table 4.18 Support system

| SUBCATEGORY | MEANING UNITS |
|---------------------------------|--|
| 4.11.1 Support system (F114) | The families come together to give each other support ... to prepare for the future of both the family and the patient. (I2) |
| (F111) | Alzheimer's Association helps to provide assistance ...places patients for respite or provides care on a daily basis. (I1) |
| (F113) | Family is a support system for nurses. (B2) |

4.12 CONCLUSION

This chapter discussed the data analysis and findings, including categories, codes and themes, with reference to the literature reviewed. Chapter 5 concludes the study and makes recommendations for practice and future research.