

Unacknowledged afflictions

**The essentials of the experience of people with persistent
pain in nursing homes**

-A phenomenological study-

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Guðrún Dóra Guðmannsdóttir
Student number: 9800931

Supervisor: Professor Sigríður Halldórsdóttir
RN, MSN, PhD

This dissertation is submitted to the RCN Institute in part fulfilment of the MSc in Nursing and has been conducted and presented solely by myself. I have not made use of other people's work (published or otherwise) and presented it here without acknowledging the source of all such work.

Garðabær, 20th of November 2001

Guðrún Dóra Guðmannsdóttir

Dedicated to my aged mother who taught me genuine respect for the old and who always has abundant love and concern for others in spite of her own persistent pain.

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Abstract

Persistent pain among the elderly is a major health problem within nursing homes. There is new knowledge, mainly in pharmacology, on pain assessment and management of this age group. Geriatricians claim that with quality pain management a relevant goal is to provide considerably relief and in some cases a pain-free state of those that now suffer. Certain attitudes of the elderly are known to bias pain assessment. The purpose of this study was to examine the lived experience of elderly residents with persistent pain in nursing homes. The research approach used was the Vancouver school of doing phenomenology. Data were collected in open interviews or dialogues. The research question was: 'What are the essentials of the experience of people with persistent pain in nursing homes'? The sample was twelve residents, mean age 86 years. After analysing the transcribed data, themes were constructed. The overriding theme was is '*Unacknowledged afflictions*'. Three major themes were constructed. The first theme: *Reconciliation to losses in life* refers to the fact that residents tended to see their pain in a wider perspective of losses in life. They reiterated losses of loved ones, of health and former home. An ongoing work of reconciliation and adjustment seemed to be going on within them, many could be placed on a continuum between grief and even anger at one end genuine peace on the other. The second theme was: *the lived experience of persistent pain* with the subthemes of : *All in control*, *Seeks help when needed* and *Reluctant to seek help*. Some felt everything was under control and of which the doses of tablets seemed to be a token. Others had no problem with seeking help when needed. One resident did seek help in vein. A few were reluctant to seek help and seemed to have become lost or unacknowledged from the eyes of the doctors or nurses. This seems a group in obvious need for help. The third major theme was: *Sources of strength and joy*. These were mainly close relatives, enjoying reasonably good health and conditions of living. Suggestion is made that nurses will look at persistent pain in the aged in the context of the multiple losses and grief. Residents without needed help must be found. Under all circumstances should the words of the sufferer be counted as valid.

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Chapter one

Introduction

1.1. Introduction

In this initial chapter I will explain the purpose of the study, its methodology and sample and describe the research question. I will present the criteria and background of the study; illustrate its significance and what evoked my interest.

1.2. Purpose

The purpose of this study was to examine the lived experience of residents with persistent pain in nursing homes with special emphasis on their pain and discomforts as well as to explore the meaning they give to their experience.

1.3. Methodology and sample

The research approach was interpretive/constructivist phenomenology. The Vancouver school of doing phenomenology was used. Data were collected in open interviews or dialogues with the residents and analysed according to the Vancouver school of doing phenomenology. The sample consisted of twelve people; mean age 86 years, residents in three different nursing homes in Iceland. On the average, there were two interviews with each co-researcher.

1.4. The research question

In thinking of the research question, I started by asking myself the fundamental question of what; in essence it was that I wanted to know more of in the area of pain management and old people (Valiga and Mermel, 1985). I came to the conclusion that I wanted to get a deeper understanding of the real life experience of old people concerning their pain and related discomfort. Furthermore, I wanted to apprehend what meaning they give to this experience. The research question therefore was: **‘What are the essentials of the experience of people with persistent pain in nursing homes’?**

Then I chose a research approach that seemed most appropriate to answer this question. As interpretive phenomenology by definition tries to inquire how people construct inner consciousness and meaning, that methodological approach was chosen.

1.5. Criteria

The reason for including only residents in nursing homes, but not the elderly in the community as a whole or those in old people’s homes was that I wanted to inquire about the group of people that usually have to depend solely upon the health care staff for their pain relief.

The **definition of pain** used here is persistent pain, chronic, not acute, that has lasted for at least three months. There is no reference to origin or prognosis. It can be either constant or intermittent pain but in all cases it has an impact on daily life of the resident according to information from the respective ward sister (see Appendix IX). No assessment was made of the quality of the present pain management intervention

The origins of the pain usually was connected to the most common illnesses of old age like arthrosis, low back pain, pain as a result of Parkinsonism or of

vascular insufficiency in the legs and abdominal pain of unknown origin. My inquiry was aimed at the physical pain especially, although I was aware that discomforts of psychological, social or spiritual origin can be intertwined with physical well being and would most likely be expressed in the dialogues, too. The evaluation of **the intensity of the pain** rests with the individual. This is in accordance with a well known definition within nursing which stresses the subjective nature of the pain experience: ‘ Pain is whatever the experiencing person says it is, existing whenever he says it does’ (McCaffery, 1972, [p.8], cited in Bergh & Sjöström, 1999). Other criteria for taking part in this study are described in Appendix VIII.

The word **discomfort** is used together with the word **pain** since people tend to express themselves with a variety of words for pain-related hurts and I wanted to give room for that. A ‘pricking sensation’, for example, can be an expression of much pain for one individual. In this study, the focus is on residents who still can communicate adequately. Communication breakdown in some measure is evident in a big group of nursing home residents. Cognitively impaired geriatric patients are outside the scope of this study.

1.6. Background of the study

A number of researchers claim that chronic pain is a major health problem among the elderly, both in the community and within nursing homes (McCaffery & Beebe 1989, Walker 1995, Ferrell 1995, Weiner et al. 1999). Some of them point to evidence that seems to indicate that pain in old age has been considerably under-diagnosed and under-treated in recent decades. Unfortunately, most health conditions that are common in old age are comparatively painful and chronic in nature, such as different kinds of arthritis, low-back pain, osteoporosis and post-fracture conditions. Furthermore, it must be remembered that old people often have more than one source of pain.

There has been little clinical research on pain among the old and they themselves have had scarce representation in such research (Ferrell et al., 1990). During the recent years, however, more research among this age group has been carried out and new knowledge on quality pain management among the elderly has come forth (Helme 1997, McCaffery and Pasero 1999). There is an indication that there exists a considerable discrepancy in the self-assessment of pain by the patient on one hand and the assessment of nurses or doctors on the other hand. This is usually in the direction of underestimating the patient's pain, which suggests that pain goes under-diagnosed and under-treated to some extent among the older generation. At the same time, physicians claim that with alert and timely pain assessment and effective medical and non-medical pain management procedures, it should be possible to provide considerable relief in most cases or even cure (Wagner et al., 1997, American Geriatrics Society 1998, Leland 1999).

Furthermore, it seems the old person him-/herself can be a block to good pain assessment and management, knowingly or not. This is an important fact for the health professional to realise. If the old person conceals his or her pain for some reason no quality pain management can be attained. An example of a possible bias is untimely resignation to the pain due to the notion that pain inevitably increases with age and nothing can be done about it (Yates, Dewar and Fentiman, 1995). The side effects of under-treated pain must be taken into consideration, too, including for example depression, sleep disturbances and mood changes. Therefore it is important for health professionals to explore the lived experience of pain and discomfort in old age.

1.7. Aim of the study

The aim of this study is to get a better understanding of the lived experience of elderly people who have persistent pain and are residents in nursing homes, and what meaning pain and discomfort holds for them; hoping to obtain knowledge

that might be of help for better pain assessment and effective pain management among this group of people.

1.8. Significance of the study

Pain is a big health problem in geriatric nursing. In one study, 71% of residents in nursing homes complained of pain, of which 34% described having constant pain and 66% intermittent pain (Ferrell et al., 1990). In Iceland, I have not yet found actual epidemiological studies on pain among this age group, but the RAI assessment tool (See further in Chapter 2.4.1.) gives valuable information, which seems to indicate that 40% of residents have pain every day and another 34% have pain more seldom.

The number of older persons will be growing rapidly in the western countries during the next few decades, both in proportion and in actual numbers. In Iceland, for example, in 1995, there was around sixteen thousand people age 67 and older (which is the age for being pensioned by the state). It is estimated that in the year 2030, almost thirty thousand people will be in this age group, which means an increase of almost 100% in 35 years. Such numbers are not and will not be seen in other age groups. Around 10 % of people in this age group are presently living in nursing homes in Iceland (Statistics Iceland, 1995).

Health problems of elderly people are often painful and persistent. At the same time there seems to be some reluctance among the elderly to seek help for their chronic pain and to report it (Ferrell et al., 1990, Yates, Dewar and Fentiman, 1995). One explanation that has been mentioned is certain negative attitudes towards ageing such as the notion that pain inevitably follows old age and nothing can be done about it. It must also be remembered that pain is essentially a subjective and personal experience and therefore only the patient can tell of its intensity and duration.

1.9. What evoked my interest?

In my practice as a geriatric nurse, I have been aware of a need in this field to assess pain more accurately and manage it more systematically. An ongoing re-evaluation of the treatment must not be forgotten, either. I have wondered about the acceptance and undisturbed attitude of elderly people concerning different health problems and why they often do not initially expect any help with their pain.

A recent study from Sweden evoked my interest. This was a comparative study by Bergh and Sjöström (1999) of nurses' and elderly patients' ratings of pain and pain tolerance. It clearly brings forth a considerable discrepancy of the assessment of staff versus the self-assessment of the patients. Thirty-nine nurses from nine geriatric units in a university hospital participated, and the same number of patients. A visual analogue scale (VAS) was used with descriptions of pain from 'no pain' to 'the worst pain imaginable'. The patient used the scale and was interviewed by a researcher. Right afterwards, a nurse from the ward came in, assessed the patient's pain and recorded it on a similar scale afterwards.

The results were somewhat disturbing. The nurses tended to rate pain considerably lower than the patients did. The nurses' ratings had only a moderately positive correlation overall with the patients' ratings. Seven patients rated their pain from 61-100 on the VAS, which is quite intense pain, but in those instances there was virtually no correlation between nurses and patients' ratings. The researchers ask if nurses, through constant exposure to pain, possibly have changed their frame of reference. They also wonder if nurses realise the difference between the signs of acute and chronic pain. Bergh and Sjöström (1999) claim that there is a great need for well-defined guidelines and routines in geriatric care to detect, assess, treat and document patient's pain.

Studies among physicians have revealed a discrepancy in the same direction in pain assessment as among nurses (Sengstaken and King, 1993). See further in chapter 2.6.2.

1.10. Creating a framework

In this study I wanted to seek some explanations of this discrepancy from the resident's side, although the side of the staff is important too, and these two sides have an impact on one another. Important questions come to mind: Is there something in the attitudes or beliefs, or overall outlook on life that affects the expression of the old person's needs? Is there some other block in communication on the part of old person in pain that health professionals need to be aware of? What about present routine assessment by registered nurses? Is it misleading in some subtle way? Information from residents themselves must have much bearing here.

Therefore, in this study, I wanted to examine the experience of elderly people with persistent pain who are residents in nursing homes, and focus especially on the meaning they give to their experience and attitudes connected with it.

1.11. Summary

In this chapter I have explained the purpose of this study, its methodology and sample and described the research question and criteria. The background and significance of the study were presented and a framework put forth.

Chapter two

Literature review

2.1. Introduction

In this chapter I will give an overview of the research I could find pertaining to the phenomenon under study here, and thus try to summarise what is already known on the subject of persistent pain and the elderly nursing home resident. First I will discuss pain and the elderly, some psychosocial factors in pain assessment, blocks to effective pain management and lastly the experience of living with persistent pain.

2.2. How the literature search was done

Different computer databases were used to search for articles, primarily research or review articles. The time limit was set from 1990-2001 except for a few influential older articles. The databases were deliberately from different professions since I decided to look at pain in a wide perspective.

The databases MEDLINE, CINAHL, CancerLIT, PsycINFO and SocioFile were used. The initial key words in the search were: chronic pain, elderly, nursing homes, pain assessment, but also related words like: geriatrics, pain management, chronic illness, pain, nursing service. Later in my search I included variables like culture and gender differences in pain expression. I also made use of some clinical guidelines in nursing and medicine on the matter of pain management and the elderly.

2.3. How the literature review will be organised

The literature review itself is divided into four parts. First of all there is a discussion on persistent pain and elderly people (2.4.), the size of the problem, relevant management goals and a need for a reliable assessment tool. Secondly I will reiterate some psychosocial factors within the nursing home (2.5.), the expression of pain, possible cultural and gender differences and power-related factors. Thirdly there is a discussion on possible blocks to effective pain management (2.6.), like attitudes and beliefs of the elderly themselves, misconceptions and lack of knowledge of staff. Finally I will describe the actual experience of persistent pain according to three studies I found on this matter (2.7.).

2.4. Persistent pain and elderly people

2.4.1. The size of the problem

Compared with other age groups, elderly people as a group have had scarce representation in medical research on the whole (American Geriatric Society, 1998) and their pain still less. In the year 1991, Melding observed that as each year over 4000 papers (MEDLINE data) were published on the subject of pain, but less than 1% of them focused on pain experience or pain syndromes in the elderly person.

I am greatly indebted to Ferrell and Ferrell who have been among the leading researchers on the matter of pain and the elderly in nursing homes the last decade. In 1990, Ferrell et al. (Bruce Ferrell, Betty Ferrell and Dan Osterweil) published an article they call 'Pain in the nursing home' and much has been

referred to, where they point to the size of this problem. This prevalence study of Ferrell et al. (1990) was done in a teaching nursing home in the USA. Ninety-seven residents were interviewed, and charts were reviewed for pain problems and management of these problems. Results indicate that **71% of the residents had at least one pain complaint**. Of those with pain, 34% described constant pain and 66 % intermittent pain. In addition, more than a third of those with pain had more than one source of their pain. Functional correlates of pain were observed in this study, too. Pain impaired the ability of 54% of the residents to enjoy activities in the facility, like religious, recreational and social activities, another 53% reported impaired ambulation and 45% mentioned sleep disturbances. Ferrell et al. (1990) point out that there is a high prevalence of pain in long-term care settings and current pain management techniques are only partially successful in dealing with the problem. They claim that pain is a distressing problem at any age and that: ‘Salient goals of care for elderly people in long-term care settings should be the comfort and control of pain’ (p. 413).

Several studies of pain prevalence among elderly in the community show that pain increases in prevalence from early adult years up to approximately 60 years of age. Then it reaches a plateau and may even decline in extreme old age. The question rises then whether possibly this is because people complain more seldom or the pain actually ceases. Helme (1997) points to the increase in dementia as one explanation of reduced pain report.

In Iceland, the RAI- assessment tool gives valuable information. RAI =Real Assessment for Inhabitants is an international quality assessment tool, where nurses and other health care professionals collect data which is published yearly, on the situation within the healthcare service among the elderly. The Icelandic Ministry of Health and Social Security was the initiator of RAI. The prevalence of pain in nursing homes in Iceland for the year 2000, according to the RAI assessment is **40 % of residents having pain every day** and **34 % having pain more seldom** (Icelandic ministry of health and social security, 2000). Only 27 % seem to be completely without pain. The intensity of the pain is also described: sometimes bad/unbearable 15%, middle intensity 57 % and little pain 29 %. It

must be remembered, though that this is according to the nurses' estimation, not necessarily interviewing the resident or using special pain assessment tools.

2.4.2. Relevant management goals

What are relevant management goals for people in old age? The notion that pain and old age inevitably go together are considered among the myths that have been barriers to good pain management among the elderly through the years (McCaffery and Beebe, 1989). Clearly good pain assessment, which most agree is the beginning of effective management of pain, is not always simple. There seem to be different barriers for the improvement of pain management in clinical practice. On a larger scale it can be attitudes in the society and economics together with medical and nursing education. At the same time, high prevalence of dementia, sensory problems and disability make the assessment of each individual comparatively difficult in this population (American Geriatrics Society, 1998). The elderly themselves may also present substantial barriers to accurate pain assessment due to certain personal attitudes. According to Ferrell & Ferrell (1992) a priority in geriatric care should be the control of chronic disease symptoms, improvement of comfort and preservation of personal dignity. It is claimed that if health care staff is alert for chronic pain and start treatment early, with medical or non-medical means, it should be possible to lessen pain considerably in many cases and sometimes cure it completely (American Geriatrics Society 1998; Leland 1999; Wagner et al. 1997). In accordance to this better results could be reached in chronic pain management among elderly people.

Quality management of chronic pain in older people of any age group should definitely be our goal, both of professional and ethical reasons. The consequences of persistent pain are varied and tend to give rise to new problems. Depression often is associated with pain in older persons, decreased socialisation, sleep disturbances and impaired ambulation, together with gait disturbances and adverse effects of multiple drug prescriptions, to mention a few side effects (American Geriatrics Society, 1998).

Ethically, people of all age groups must have the same right to high quality pain management. There has come new knowledge in medicine on analgesics and old age that indicates that former fear of adequate analgesics and narcotics for the aged is not valid any more (Ferrell et al. 1990, McCaffery and Beebe 1989, American Geriatrics Society 1999). But this knowledge does not seem to have entered clinical praxis adequately, yet. Copp (1993) states that there are well-documented instances of both under-prescribing of analgesia by physicians and under-administration by nurses of ordered pain medication. Besides, every single nurse may assess a 'need' for pain relief differently. Copp points out that in hospices, health professionals have made the moral judgement to relieve their patient's pain unconditionally and within the parameters of sophisticated pain management and nursing care. She asks: 'Can we accept the challenge in hospitals, nursing homes, out-patient clinics and in the home to manage pain as an ethical and professional imperative'? (p.2). This ethical challenge is worth much consideration.

2.4.3. An assessment tool is needed

An assessment 'tool' of pain is some kind of a screening tool for pain. It can be a questionnaire, a visual scale of some sort or other methods of inquiry. Quality assessment of the pain, with a method that fits this age group is a prerequisite for effective pain management. Some research has been done to find such a tool. Weiner et al. (1999) examined the utility of the pain map for frail nursing home residents. The person then needed to point to the site of his or her pain on a map of the body. This gave good results, also among many cognitively impaired persons. A suggestion was made that such a pain map should be a part of the admission assessment battery, which would keep the nursing staff more knowledgeable of the pain sites of their client.

Another interesting research in this direction done by Axelsson et al. (2000) in Sweden is worth consideration. They designed and used a certain method or assessment tool that proved effective for old people, including those with

communication problems due to dementia or following a stroke. The study included 66 elders in a nursing home of which 49 % had dementia as the main diagnosis. A specially trained nurse made a pain assessment by combining interview and observing the person's reactions during activity. In addition physiotherapists performed physical examination including joint motion and palpation of joints and muscles. **Results were that pain was identified in 88 % of the residents**; only 42% of them were treated with analgesics at the time of the study and pain was documented in the nurse's notes in for only 27 % of the patients. These results indicate that much more patients with pain can be found when good pain assessment tools are used. This method even proved effective for the demented elderly. It is my view that the study of Axelsson et al. presents a valuable tool that seems fit for frail old people. I will discuss this study further in Chapter 6.7.

2.5. Psychosocial factors within the nursing home

2.5.1. The expression of pain

Unfortunately a big part of residents in nursing homes have seriously impaired possibility to express their pain due to e.g. dementia or speech disorders as a result of a stroke. It has been estimated that up to 70% of nursing home residents are cognitively impaired or have other problems of communication (Icelandic Ministry of Health and Social Security, 2000). This fact presents other problems not directly within the scope of this study since here I focus on residents that still have the ability to communicate.

Another issue needs clarification here, which is the attitude of professionals towards what chronic pain essentially is and what is the responsibility of the sufferer in his own pain. In other words: Is cognitive-behavioral management relevant for pain in old people? I decided to keep that concept out of this research for two reasons. First of all, the focus group of this study is frail individuals. Some of them would not have cognitive ability to take part in such

management. Secondly, in this study I stress the self-evaluation of the patient of his or her pain and consider mainly pain of physical origin but not pain with no known physical cause.

In this study, pain is seen as the result of organic, psychological and possibly also social factors. Physical pathology is a necessary determinant but other factors are seen as contributing to the final expression of pain. Grounds on which different management schools are based are varied, mainly pertaining to if the patient is held responsible for his or her pain or not. I tend to agree with Keefe and Caldwell (1997) who explain the hallmarks of a bio-psychosocial model for understanding arthritis pain. Such pain, they maintain, not only is influenced by biologic factors e.g. the degree of inflammation or joint destruction but also by psychologic factors e.g. depression, fear of unpredictable pain flares and social factors e.g. the presence of a supportive home environment.

I believe, on the other hand, that we cannot normally hold old people personally responsible for their pain or reactions of pain, due to their age and frailty. Besides they often do not have the cognitive ability any longer to take part in a cognitive -behavioural management of their pain. Also, I think it is of grave importance to believe our clients' descriptions of their pain (Eccleston et al. 1997). I will argue that at this point in life, the professional's role is rather to act as a support person who encourages the elder to receive appropriate help.

2.5.2. Cultural and gender differences

There are indications that cultural differences both might bias the sufferer's expression of and the professional's attitude towards and assessment of the client's suffering. Bates et al. (1997) have done an interesting study of cultural differences in professional's responses to patients' problems, in the relationship between patient and provider and the patient's response to chronic pain and illness. Groups in Puerto Rico and New England were compared. In the New England groups, the biomedical worldview of mind-body dualism was dominant among patients and providers, but this shared belief often contributed to substantial patient stress and alienation. On the other hand, the Puerto Ricans, both the patients and providers did share a view of mind-body integration in

illness and valued treatments, which considered chronic pain as a bio-psychosocial experience. Here, shared views of patients and staff contributed to more supportive patient- provider relationship. Bates et al. (1997) claim that when provider and patient worldviews concerning pain are not similar, 'miscommunication, diminished quantity and quality of treatment, and an ongoing process of reduced quality of life for the patient is the ultimate outcome' (p. 1440).

Concerning gender differences in the expression of pain, there is an indication that males are in more danger of under-diagnosis of their pain than females. Won et al. (1999) did a cross sectional study in nursing homes in four US states. They had almost fifty thousand residents in their database. As daily pain was reported in 26% of nursing home residents, the prevalence was lower in males, people over 85 years and racial minorities. Approximately 25% of persons with daily pain received no analgesics. Males were at greater risk of not receiving analgesics together with the cognitively impaired, racial minorities and those over 85 of age. Even when the pain was recognised, men, cognitively impaired residents and racial minorities were at greater risk of under-treatment. This observation is disturbing but similar things have been documented in other research, too (Bernabei et al. 1998). It is noteworthy that in the study of Won et al. (1999) the oldest old seemed to be in danger of under-diagnosis, too.

2.5.3. The silencing effect of pain

Whose voice matters in the pain account? Is it the sufferer's, on one hand, or the physician's, nurse's or the institution's on the other hand. More research is needed in the area of power, socialisation and culture within institutions. In a political connection, Scarry (1985) has described how regimes of states can 'unmake' an individual's world by causing physical pain, like in torture, and in that process rob the sufferer of the ability to verbally describe his or her anguish.

Although on a smaller scale within a health institution, many people in all ages seem to witness how difficult it can be to communicate pain. Pain forces us to

‘feel the feeling’. Strangely, chronic pain is a sensory sensation with no object. Even though the stimulus of the pain originally comes from an outer object like a knife for example, that object is thrown away and does not reveal or objectify the pain as such. Pain is a subjective feeling of a subjective experience although the cause of the pain is objective and known. Scarry states that pain achieves its aversiveness in part by bringing about the split between one’s sense of one’s own reality and the reality of the other person. Thus to be in pain is to have certainty while hearing about pain almost habitually calls for doubt in the listener. Some consequences of pain in a person seem to be because of this unsharability of this phenomenon. Some silencing effect commences. Is it possible that this is the experience of some of our clients within geriatrics?

Vrancken (1989) points to the ‘pain’ of medicine itself, as she puts it. As man has natural impulses to react to pain, the behavioural school has essentially substituted this reaction for another, usually some rewarding behaviour, so this school fights against the pain behaviour instead of the pain itself, she claims. Medicine as a profession is in a way silenced because it cannot nominate pain. Medicine similar to the chronic pain patient is driven and captured by pain. ‘In seeing this, in living through its own pathos...medicine would be able to lift pain out of the order of things. Its passion for pain need not to exclude compassion’ Vrancken states (p. 443).

2.6. Blocks to effective pain management

2.6.1. Attitudes and beliefs of the elder

As explained in the introduction, there seems to be many barriers visible and invisible to good pain management. Ferrell et al. (1990) observed in their study significant attitudinal problems in the reporting of pain by elderly patients. One prevalent barrier is that some people seem to expect pain with ageing as inevitable and therefore do not tell about but endure in silence. Notably, Ferrell et al. (1990) believe these findings imply that if the patient is not asked especially about specific pain symptoms or effects, those problems will go un-

identified or under-diagnosed. Some of this untold pain could possibly be successfully treated. My own experience with the aged supports this view.

Hofland (1992) writes a thought-provoking overview of beliefs of elders, which possibly could be a block to pain management. She points out that just as nurses are influenced by their beliefs when doing a pain assessment (Dalton 1989) it seems logical that patients are influenced by their own beliefs and values when responding to a pain assessment. Health care staff should be able to recognise such beliefs, since if not incorporated into the pain assessment, the real problems and diagnosis cannot be made.

Some of these blocks could be according to Hofland: A passive patient role assumed, including reluctance to complain about pain, or out of fear to be labelled “ a bad patient”, or even of extreme trust that the nurse knows without being told. Another could be that the patient’s self-concept is violated if complaining e.g. if coming from a culture of stoicism. She also mentions if patient believes that the staff is too busy or not interested to listen to complain. Lastly she mentions the well-known view that pain is a normal and inevitable part of ageing and so should be expected and tolerated and thus might go under-reported or not reported at all. Ferrell et al. (1990) got very similar results in their inquiry on the question why participants did not ask for medications for their pain.

2.6.2. Misconceptions of staff

The under-treatment of pain in elders has shown forth in recent literature. Not only nurses but also physicians and other staff too, seem to hold on to some misconceptions that do not have a scientific ground (Sengstaken and King 1993). Why is it that old people frequently seem to be treated less aggressively than younger patients are by no scientific reason? According to research, there are some misconceptions or old knowledge still around. One is the fear physicians and nurses voice that the old person will become addicted if narcotics are

administered. This goes on in spite of the fact that less than 1% of those taking opioids become addicted (McCaffery & Beebe 1989, Ferrell et al. 1993). Another myth is that pain is a natural outcome of growing old, as mentioned before. Pain is not an *inevitable* part of ageing and its presence necessitates assessment, diagnosis and treatment as in other age group (McCaffery and Beebe, 1989). Then the whole body of the aged would be in pain not only one leg for example, since they are both of the same old age, McCaffery and Beebe argue. The third is that pain perception, or sensitivity decrease with age. In chapter 1.8. some misconceptions of staff (Bergh & Sjöström 1999) in pain assessment are described.

A study concerning bias by physicians is by Sengstaken and King (1993) who wanted to assess physicians' detection of pain among geriatric nursing home residents. They viewed charts of 100 elderly people in a nursing home and did patient interviews. Seventy-six were able to communicate, and twenty-four not. The communicative ones who were identified as having chronic pain were 66% - which notably is not different from what Ferrell found (71%). Treating physicians had detected pain in 43% of these residents. In fact another seven denied pain on interview but had been recognised as having that on the doctor's notes. Of those seven, five were receiving analgesic medication on daily basis. In the group of hidden sufferers there were many with neurological disorders, like Parkinson's disease and cerebro-vascular accidents. The authors therefore suggest that such patients possibly would benefit from being asked *repeatedly* about their pain, due to fluctuating mental status. Twenty-four were not communicative and out of those the treating physicians had detected chronic pain only in four (17%).

There is no description of the data collection interviews in this study, which in this population is quite prone to bias. There was not a physical examination done but reliance on patient charts, older information. The dispensation of PRN medicine might rather give a picture of nurses' detection but not the physicians of pain, so possibly there is even more mismatches among the physicians.

2.6.3. Lack of knowledge of staff

Pain experts have pointed out areas that seem to influence most heavily the actual clinicians' practices, as being different beliefs and misconceptions on pain and unfamiliarity with current research. Nurses, as primary care providers must be essential in the process of pain relief. Still, studies have documented that nurses, physicians and other health care professionals sometimes seem to be inadequately prepared to care for patients in pain. Explanations have been sought in the education of these groups, lack of curriculum contents on pain and, not the least, attitudes and beliefs of staff, related to pain.

Closs (1996) did a postal survey among qualified nurses in four types of clinical areas on their knowledge and experience of pain and pain control in elderly people. There were three different surgical spheres and one was care of the elderly. Response rate was 55%. Some answers were disturbing. One third of the nurses believed that pain and discomfort were unavoidable consequences of ageing. This notion is one of the dangerous myths of ageing (Watt-Wattson and Donovan 1992, McCaffery and Beebe 1989) which could and has led to neglect of pain that might otherwise be treated.

In Iceland, Thorsteinsson and Hafsteinsdóttir (1994) did a survey on the knowledge of Icelandic nurses of pain, pain medication and the advantages of regular administration of pain medication. There was a random sample of 743 nurses, and the 68% did take part. On the average the nurses answered 59% of the knowledge-questions right. Less than 10% answered more than 80% right. There was most prominent lack of knowledge in the area of pain medication. Furthermore, there were some old myths still around and the nurses showed some ambivalence towards believing the patient who complained of pain.

2.7. The experience of living with persistent pain

2.7.1. Do older people than younger experience pain differently?

Much seems to have been written on the question if pain is experienced differently in older people than younger ones. Helme (1997) reminds that it is not the case that older people feel less pain, only that possibly the threshold for pain is elevated. On the other hand Helme maintains that the reaction, psychological and social might be slightly different.

Ferrell (1996) cites a review of the subject of changes in pain perception by age done by Harkins (1996) who concludes that significant age-related changes in pain perception probably do not occur. Ferrell (1996) warns that in the final analysis, the consequences of stereotyping elderly patients as experiencing less pain may lead to inaccurate clinical assessment and needless suffering. Ferrell further points out that the clinical significance of such studies is questionable since induced pain in a laboratory setting may not be analogous to pain caused by disease. In 297 pain clinic patients ages 18-90 (Ferrell, 1996) there was no apparent age related differences in pain, neither in sensory, affective or in depressed mood. On the other hand there were some differences in anxiety level, pain impact and coping style with age (Corran et al. 1994).

2.7.2. Three different studies on pain experience

Lastly I will introduce three studies on the lived experience of pain among elders. These studies lie close to my own study even if the methodology is different.

I. People in pain oscillate between endurance and anguish, tendency to isolation and comforting engagements and hope for relief according to Carson & Mitchell (1998) who did an exploratory study with 17 people living with persistent pain. The purpose was to enhance understanding of life lived in the shadow of much and persistent pain, seen from the perspective of those who live it. Physical pain

as well as the pain of loss and restriction is described. A descriptive exploratory design was used to answer the research question: What is the experience of living with persistent pain. Health care professionals identified potential participants. There were 10 women and 7 men, age from 54-93 years. Twelve people lived in a long-term care setting in a hospital; others were outpatients or in hospital for a short stay. The interviews were average 30 minutes in length. The findings are put forth in three themes capturing the essence of living with persistent pain:

1. Forbearance surfaces with the drain of persistent anguish. All participants spoke of the difficulties of living with such pain, how horrible and relentless it was and described how it had changed their lives. And yet they indicated that they found the strength to bear with it and endure the discomfort.

2. Isolating retreats coexist with comforting engagements. Here they described self-enforced withdrawal from usual activities and also ways they found to participate in activities that were comforting. But at the same time the pain never completely went away. Paradoxically, sometimes people wanted to express their pain and sometimes hide it (like for dear family members).

3. Hope for relief clarifies priorities of daily living. Participants described their hopes related to comfort and relief and spoke of different ways how they managed to go on. Feelings of loss were clear when people talked about what they had to give up to live with the pain.

II. Discussions in focus groups were initiated by Yates, Dewar and Fentiman (1995) in a study of the view of elderly people living with pain in long-term residential settings on pain and pain management.

There were ten 60-90 minutes focus group interviews with five people in each group in four large residential settings. Results indicate that these people may have become resigned to pain, they are ambivalent about the benefit of any action for their pain and that they may be reluctant to express their pain. Improved assessment and more effective pain management are important together with continual re-orientation that pain does not have to be a normal consequence of ageing. However, this research has implications for nursing.

III. In a descriptive phenomenological study by Thomas (2000) thirteen people living with chronic pain described their experience. Participants were 27-79 years of age, nine females, and four males. These chronic pain patients described their experience as an individualised dialogic process between themselves and their painful condition. Their world became smaller and their freedom greatly constricted. Pain dominated their consciousness. These people were always aware of the pain. There was an altered perception of the body and less self worth. A separation from other people was prominent, - few wanted to listen and they complained seldom. They hoped for a good doctor but often experienced that doctors do not listen. There is an existential crisis within many of them. These people seem to have had much pain; but no objective assessment seems to have been done. Nurses are invisible here. The controversial methodological concept of bracketing is only mentioned but not explained further. The conclusion of Thomas is interesting and important for the nursing profession, however: It is a call for more skilful psychosocial care for pain patients. 'The psychological pain of being disbelieved and stigmatised is surely as devastating to these patients as their bodily pain, perhaps more so', Thomas concludes (p. 687).

2.8. Summary

In this literature review, I have attempted to give an overview of the problem of pain in the institutionalised elder. The size of the problem and relevant management goals was cited. Psychosocial factors within the nursing home were reiterated together with some blocks to effective pain management. Lastly the experience of living with pain was described.

Chapter three

Methodology and methods

3.1. Introduction

This chapter presents an explanation of the sample, a short description of phenomenology as a philosophy and research approach. Then I will describe the Vancouver School of doing phenomenology and why it was chosen in this study. Finally there is a clarification on how rigor was ensured.

3.2. The research question

As stated in Chapter one, the purpose of this study is to examine the lived experience of residents with pain and discomfort in nursing homes as well as to explore the meaning they give to their experience. The actual research question was ‘What are the essentials of the experience of people with persistent pain in nursing homes’?

3.3. The sample

The sample was purposive; twelve elderly people; seven males and five females. There were two research dialogues with each participant, except in two cases when only one dialogue was carried out, and in one case three dialogues; on the whole twenty-three dialogues. The study was carried out in three nursing homes

in Iceland. I tried to have these nursing homes somewhat typical for Iceland, not those in connection with the biggest hospitals and not the smaller ones either. In order to preserve confidentiality, a further description of the nursing homes in the study will not be given, due to our small context

3.4. Phenomenology as philosophy and methodology

Although knowledge within the health sciences, to a great extent, has been gained through the traditional method of natural sciences, certain aspects of human life cannot be studied in the same way as parts of the physical world (Lucock 1998). Therefore, in human sciences and especially when we want to get to the core of human experience, other methodologies have been developed. Phenomenology is one of them. I will make use of Vancouver School of doing phenomenology which is a school within the realm of an interpretivist/constructivist phenomenology.

Phenomenology, as a research methodology in human sciences, has gone through considerable development. Husserl, a German philosopher in the early twentieth century is generally thought to be the founder of phenomenology. He introduced the concepts of 'lived experience' and 'essence'. 'Bracketing' is also a concept originated from him and is used for the endeavour to obtain objective knowledge without influence from the researcher. Husserl claimed that researchers could stay apart from the research; they could discard or 'bracket' their natural attitude. After Husserl, phenomenologists like Heidegger and others, maintained that researchers would inevitably in some sense make interpretations and put their own values into the research. However, within the interpretive school it is of importance to acknowledge one's preconceived ideas beforehand and try to minimise their influence on the study, realizing that this is never fully possible or even desirable.

Gadamer used the notion of 'prejudgements' in this connection and encouraged researchers to test those 'prejudgements' by exposing them to the 'prejudgements' of others with different backgrounds to our own. This would be done when people share different experiences with an open mind. He described

this as a fusion of horizons and claimed that by doing this we would widen the horizons of our knowledge. In other words we modify our 'prejudgements' into new knowledge in such interaction (Lucock 1998). The dialogues with the co-researchers according to the Vancouver school can be an excellent opportunity of such fusion of horizons.

What, in essence, is phenomenology, then. In his book on the history of phenomenology, Spiegelberg (1982) tries to find a common core among phenomenologists that would justify the use of a common label. Despite diversity and lack of definitions, Spiegelberg claims that the actual method phenomenologists use in research that essentially make the frame as to what is phenomenology and what not. The phenomenological approach aims to enlarge and deepen the range of man's immediate experience, it wants to give the phenomena under study: 'a fuller and fairer hearing than traditional empiricism has accorded them' (Spiegelberg 1982, p. 680). An important word of caution from Spiegelberg is to beware of preconceptions like quick and shallow use of principles. He claims that on the contrary it takes 'a determined effort to undo the effect of habitual patterns of thought and to return to the pristine innocence of first seeing' (Spiegelberg 1982, p. 680).

3.5. The Vancouver school of doing phenomenology

The Vancouver School is interpretivist/constructivist school of doing phenomenology. It studies a world that is made up of meanings that affect to a great deal how people experience and live their lives (Halldórsdóttir 2000). The Vancouver School is a methodology within phenomenology based on a certain worldview and gives clear direction on how to collect and analyse the data. The works of Joan M. Anderson, at the University of British Columbia, Vancouver, Canada, inspires it. The Vancouver school characteristically shows the participants in a study much respect. They are called co-researchers, since they are the experts on their own experience. The interview is similarly called a research dialogue, since the contribution of the co-researcher is fully respected and this is a dialogue between two equals. From this dialogue comes a mutual

construction of reality that otherwise might have been hidden. This way of approaching a frail elderly person, I think is very good, since these people often need ample time and like to express themselves in a subjective and open way rather than in clear-cut questions and answers style.

The data collection and analysis overlap in the Vancouver School. Data collection starts with silence when the researcher tries to lay aside his or her preconceived ideas. The data analysis involves the cyclic process of silence, reflection, identification, selection, interpretation, construction and verification. Every stage is entered into again and again. It has built in it the hermeneutic circle originated with Heidegger and further developed by Gadamer. The hermeneutic cycle can be explained as the cyclic process of trying to understand the parts and the whole when grasping a meaning of phenomena (Halldórsdóttir 2000).

The Vancouver School then is a phenomenology intertwined with both hermeneutic/ interpretive influences from Ricour and constructivism from Schwandt (Halldórsdóttir 2000). Originally, hermeneutics is the interpretation of ancient texts. Ricour encourages passing the descriptive phenomenology of Husserl and others, and instead make use of hermeneutics to interpret the transcribed experience of people. He thus made an important contribution to the fusion of the descriptive and interpretive currents. 'Hermeneutics is not confined to the *objective* structural analysis of texts nor the *subjective* existential analysis of the authors of texts; its primary concern is with the *worlds* which these authors and texts open up' (Kearney, 1984 cited in Halldórsdóttir, 2000, p. 51).

Constructivism as explained by Schwandt claims that a new reality can be constructed in the social interaction or dialogue in the inquiry. According to constructivistic ideas, men do not so much find or discover knowledge of the world, as they construct knowledge in their minds, and then reconstruct and modify it (Schwandt, 1994). Constructivism is one of the main characteristics of the Vancouver school since within it the researcher looks at every single case first (makes case constructions) and then works on one overall construction from all the single ones, where every person has a voice. In a nutshell it can be said

that the Vancouver school makes a world appear from transcribed interviews that is made up of meanings. In practice, twelve basic steps have been delineated for this (see chapter 4.6.) and should lead to ‘a multi-voice reconstruction of the lived experience being studied’ (Halldórsdóttir 2000, p.47-48). The Vancouver school has been much used in the University of Akureyri, Iceland, in nursing research, since the 1990s.

3.6. Why choosing the Vancouver school

According to Koch (1994) any research method, deepest seen, is based on a certain world view or paradigm which can be clear or blurred but still has important influence on the study. When choosing a methodology, characteristics of the research question and its philosophical underpinnings are clarified before the methodology fit to seek answers to such a question is chosen. Then methods of data gathering and analysis that fit with the philosophical background can be determined. Therefore it is important to realise the philosophical underpinnings, or paradigms behind any research methodology used.

Phenomenology is definitely a methodology of first choice when we want to study the lived experience of people and the meaning people give to their experience (Burns and Grove, 1994). The Vancouver school wants to show social responsibility and aims at the ‘greater social good’ (Halldórsdóttir 2000, p. 53). The dialogue can be empowering in itself for the co-researcher. Its aim is to understand, to be able to serve well, often in coaching the person through a transition in life. In the Vancouver school there is characteristically a reverence for the co-researchers as persons and for their experience. This approach is in harmony with ideas of caring relationships with clients and responsible ideas of research aims within the profession of nursing.

All this influenced my choice of using the Vancouver School as a research approach. Another important point is that the spirit of reverence and silence is very fit for my sample, elderly frail people, who usually need ample time and encouragement to be able to express themselves. It seems to me that the philosophy of the Vancouver School in many ways lies close to the philosophy

of nursing. It is caring, practical and gives the client a high status and undivided attention. Dialogues, as data collection methods, seem convenient for frail elders and can be a positive experience of personal interaction.

3.7. Ensuring rigor

In qualitative research rigor or trustworthiness is achieved first of all by considering philosophical underpinnings and methodology of the coming research and adhering carefully to rules (Koch 1994). This is of vast importance, since accuracy in use of research concepts can prevent misleading decisions. Here above I have asserted that this methodology is fit for my study. Secondly, I believe, is the importance of the researcher to acknowledge her or his possible preconceived ideas and try to lay them aside as far as possible. This I tried to do in writing at different phases in the research process but especially before the data collection and analysis. Still I realise that when it comes to issues in findings that the researcher possibly has strong feelings about, preconceived ideas can have subtle influence. Different steps in the Vancouver school are important to increase trustworthiness, like the two steps of verification.

I wrote a research diary, which is strongly recommended within the Vancouver school. Such reflective diary during the time of the research not only reminds one in retrospect of how the whole process was but also shows how one's ideas have changed in the process. Such a journal can be one way of laying aside preconceived ideas (Halldórsdóttir 2000).

3.8. Summary

In this chapter I have explained the research question and sample, described phenomenology shortly and the Vancouver school of doing phenomenology in particular. I have argued that this philosophy and the worldview of hermeneutic interpretivism and constructivism are very fit for this research. Also I have explained some ways of ensuring rigor.

Chapter four

Data collection and analysis

4.1. Introduction

In this chapter I will explain the selection of nursing homes and participants, illustrate how access was sought, describe the data collection and analysis process and reflect on ethical issues.

4.2. Selection of participants and nursing homes

After having sought the necessary authorisation from the National Bioethics Committee of Iceland the research started. I was not going to use information from medical or nursing health journals so authorisation for that was not necessary. A letter was sent to the nursing directors of three nursing homes in Iceland to ask for permission to find participants for the study within their institutions. An explanatory meeting followed with each nursing director. In all cases permission was granted. Descriptive criteria were made (see Appendix VIII) for what kind of people I was looking for. Explaining these criteria in a meeting with ward sisters together with the purpose of the study proved useful. I had decided to make the ward sisters my main contacts and not to involve other staff of two reasons. First of all because of the great overview the ward sisters usually have of their patients in a wider social context, and secondly, by this I was trying to protect the anonymity of my future co-researchers within the rather small context of nursing homes.

The approach to future participants was in accordance with ethical rules, i.e. the ward sister approached the possible participant and asked for his or her permission that I would visit and explain the research, if he or she would possibly like to participate. All the nurses took care to choose people that would be able to express themselves clearly enough for this study. For a vulnerable group like frail elders, such co-operation with staff that knows them well is important. Of the group of people that were approached, three people did not want to take part; one because she had recently answered an exhaustive questionnaire from another study, one because a sudden death in the family and one gave no explanation. In one of the nursing homes it was at first difficult to find people in 'enough' pain according to my criteria, i.e. the pain having influence on their daily living, according to the assessment of the ward sisters.

In my following visits when informing possible participants, I first offered them the chance to include a relative to our meeting, but none felt that was necessary. After explaining the study according to the information sheet (see Appendix VI) all agreed to participate and signed the consent form. Later in the interviews I noticed on a few instances that for a frail elder, to write his or her name could be a major threshold and even a source of shame. In retrospect, I possibly should have encouraged the help of the ward sister or others to sign on behalf of the person more often than I did.

The actual research interview usually was one day later. Due to my experience of frail elderly people I estimated this to be the best interval, not too long so that people would not start worrying about the task at hand but still have some time to think about the matter for discussion. As a preparation for each research dialogue, I said to all co-researchers that I was interested in knowing more about the experience of elders living with different degrees of pain and discomfort within nursing homes. I also reiterated that I was not here to check on the staff or the nursing home, reminded them of my confidentiality to them and that they had the right to suspend participation whenever they liked.

4.3. The sample

The sample consisted of 12 people, 7 males and 5 females, age 74-97 years, with the mean age of 86 years. They had stayed in the nursing home from six months to nearly six years, two and a half years on the average. This was a purposive sample. At later stages I took care to include more males since some research indicate that they tend to be more under-diagnosed for pain than women (Chapter 2.5.2.).

Table 4. a. *Age and duration of stay on a nursing ward*

Sample	Age	Mean age	Duration of stay on ward
Seven men	74-97 years	83 years	
Five women	87-95 years	90 years	
Twelve co-researchers	74-97 years	86 years for all	2 years and 6 months

All the co-researchers were invited to choose themselves the most convenient place for our discussion. Six people had single rooms and chose to stay there, three of my co-researchers share room with another person; and another three shared room with two others. In all cases but one we could be alone in their rooms during the dialogues. One of co-researcher suggested the quiet place of the nursing home chapel. We had no disturbances except from thoughtful staff on a few occasions, coming in and offering some coffee.

Choosing the right time of the day is important. My experience has taught me that early in the afternoon, around 14.00 hours many elderly people usually are at their best, right after the rest. In most cases that was the time I used. The dialogues lasted from 10 minutes to 44 minutes. Average time of a single

dialogue was 23 minutes each time, and for each person on the whole an average of 46 minutes.

There were two dialogues with most of the people, except in three cases when only one dialogue was carried out. That was because two of these people gave clear information already in the first interview and the discussion seemed exhausted. I felt another visit was not needed. The third was a pilot interview, taken one and a half years before the others. At later stages of the study, when I had decided to include this interview, this participant had died so no second interview was possible. To one resident I went three times. She was frail and got easily tired but had much to share.

4.4. The research dialogue

In the Vancouver school, the relationship between the researcher and participant is characterised by mutual respect. Besides, the co-researcher is seen as an expert on the phenomenon under study, in this case his or her experience of pain and discomfort, thus the interview changes into a dialogue between two equals. This is in good correlation with the holistic view on man, prominent within nursing. To my opinion, this caring and reverent view has much value when interacting with elders, who usually feel better answering subjective and not too clear-cut questions. Besides, they often need much encouragement and time.

Many of my co-researchers were people of few words but well chosen and meaningful words. They also got tired easily, and one or two had started to forget. In the dialogues it soon became evident that most of my co-researcher tended to give an overview of their life in retrospect. They did so in terms of losses of their life. Occasionally, reasons for gratefulness and joy were expressed, too. The description of present pain and how they felt about it now did not come to the fore so easily. It repeatedly had to be asked for, both the pain itself and how they reacted with it. The pain map (see Appendix X) was of good use as a start to talk about physical discomfort. Some expressed that they found it easier that I would ask some direct questions. They sometimes remarked that they did not know if this or that was what I wanted to ask about. When the

narratives stopped in spite of my encouragement, I had some questions or suggestions for a related matter of discussion ready to start again. Some of my suggestions: ‘Tell me something about your life. How was it moving into a nursing home? How has life been for you here, with these health-problems you have now? What do you do when the pain comes? Do the nurses or doctors know about your discomfort? Do you have any other ideas on how to get rid of this pain?’ Most of my co-researchers invited me to come again if I needed more information, both after the first and second interview.

4.5. Data from ward sisters

From the beginning I decided not to use the medical and nursing health journals of my co-researchers, but to let their own descriptions stand alone, of two main reasons. Firstly, this is in connection with the philosophy of the Vancouver school i.e. to look at the participant as a co-researcher of the phenomenon under study. The dialogue partner is therefore the specialist in his or her own lived experience. Secondly, I agree with those specialists that suggest that the self-report of patients should be the most important information of the intensity of their pain. I wanted to come with an open mind to the interviews.

Still I found it necessary to verify a few matters concerning the pain management with the respective ward sister in addition to some demographic information. Therefore, a standard sheet of paper with a few questions (see Appendix IX) was laid for the respective ward sister after the dialogue concerning every participant and answered in writing. Apart from minimum demographic information there were questions on how long the person had stayed in the nursing home, if he or she received some analgesics on a permanent basis and /or PRN, if he or she received some other treatment for pain like physiotherapy etc. Then there was a question on how much influence the ward sister thought this pain had on daily life of my co-researcher (Table 4.b.).

The information from the ward sisters showed that 9 persons had analgesics on a permanent basis, and another 3 used no such medicine permanently. Analgesics ‘when needed’ came either additionally of the permanent pain relieving medicine or as first medicine for their pain. Ten people received analgesics ‘when needed’, but two people did not get PRN analgesics. This question only sounded if people *received* PRN medicine. This question does not show if it was administered by the initiative of the staff or the resident asked for it himself/herself.

When it came to other pain relieving measures than medicine only 6 persons receive or make use of such treatment according to the ward sisters. This was similar in all cases, some physical exercises and physiotherapy. In our dialogues I asked the residents sometimes if they had any other ideas of what would help to get rid of the pain. No one uttered any special opinion on that matter. See page 38, *Table 4.b. Components of pain management at the time of the dialogue.*

4.6. Self-description of co-researchers of the pain experience

A simple version of pain- mapping was done for this study. This is a sheet of paper with only three questions concerning pain, which the health care worker can inquire the pain-sufferer of. These questions are simple to understand and concern mainly the intensity of the pain, the site of it and frequency (see Appendix X). The intensity of pain is built on the Visual Analogue Scale (VAS) (American Geriatrics Society 1998) with the choice between the words: no pain, mild pain, moderate pain, severe pain, very severe pain and worst possible pain. Simple pictures of a body from front and back were used for the person to paint to the site of the pain. Lastly, people describe the frequency of their pain. On page 39 there is *Table 4.c. Self-description of co-researchers of the intensity of the pain.* It shows the descriptive words the residents chose to describe their pain. On the same page there is *Table 4.d Assessment of the ward sisters on the*

influence of the residents' pain on daily living, where the answers of the ward sisters to my question is reiterated. See also Appendix IX and X.

It is not possible to compare the self-assessment of the resident on the other hand and the ward sister on the other because the questions did not sound alike for the two groups. The resident was asked to choose an adjective that best described the intensity of his pain. This is a method that has proved effective in pain assessment tools (American Geriatrics Society 1998). The question to the ward sister was on how much impact they felt the resident's pain had on his or her daily living and activities. In five of the cases it seems the ward sister assessed the pain less. Possibly these residents were determined to let the pain have only minimal impact on their daily living.

4.7. Analysis of data from interviews.

In phenomenology the data collection and analysis usually are concurrent. I followed the steps of the Vancouver school. Step one is selecting dialogue partners and step two is silence (before entering a dialogue). The tape-recorded dialogues are transcribed and data analysed. The steps of the Vancouver school were followed onwards:

1. Read the transcript with an open mind to get a sense of the lived experience.
2. Identify key statements and increased awareness of words.
3. Identify themes of key statements. Trying repeatedly to answer the question: What is the essence of what this co-researcher is saying?
4. Grouping themes and constructing the essential structure of the phenomenon for each dialogue partner.
5. Verifying the single case construction with each co-researcher. This I could do with two co-researchers. Both were key-informants. Due to frailty of many of my co-researchers and the time that had lapsed from our dialogue, I did not go to others.

6. Constructing the essential structure of the phenomenon from all the cases.
7. Comparing the essential structure of the phenomenon with the data.
8. Identifying the overriding theme which describes the phenomenon

9. Verifying the essential structure of the phenomenon with some of the co-researchers. This I was not able to do by same reasons as in 5 above. Instead I used more time to compare the essential structure with the data repeatedly and from different angles.
10. Writing up the findings

The Vancouver school itself provides a very good opportunity for securing rigor or trustworthiness and proved fit for this study. As this sample is frail elders and a few of them starting to forget some facts, the co-operation with the ward sisters was important. Their help to select people by the criteria (see Appendix VIII) was important. On the other hand, only a little verification with co-researchers themselves was possible as I explained in Chapter 4.7. This may be a weakness of this study. However, a care was taken to be true to the data and repeatedly compare the essential structure with the data.

4.8. Ethical considerations.

In this study there were three different issues of ethical matters I found necessary to handle. First of all the need for being considerate towards their frailty, since elderly people can be vulnerable and much caution is needed to protect their rights. For example, the fatigue of the aged can be of intensity, it seems, that younger people cannot understand. On a few occasions in this study, the co-researcher was not feeling well when I arrived so we planned another appointment.

Secondly, in three instances I felt I was ethically obliged to talk to the head doctors, that is if my co-researchers would allow me. In one instance there

seemed to be a considerable under-treatment of pain based on my co-researcher's information and in another instance a person seemed too intimidated to tell about his pain, although he would like to. The third instance had to do with a certain co-researcher's negative feelings towards a certain doctor from years back, which seemed to have blocked their present communication. In two of these instances, my co-researchers gave me permission to present their cases for the respective head-doctors, but the third person did not give permission.

Finally, in one of the nursing homes I was asked to deliver the signed informed consent papers in the patient journals. The intention was to be able to have an overview of research activities within that institution. Due to the small size of the sample and context I felt that would interfere with the prospective participants' right to confidentiality, and that view was respected.

4.9. Summary

In this chapter I have reiterated that choice of nursing homes and participants, described the access to prospective co-researchers, given an overview of data collection and how the data analysis is done in the Vancouver school. Lastly there were some ethical considerations.

Table 4.b. Components of pain management at the time of the dialogue according to the ward sisters

Co-researcher	Analgesics perm.	Analgesics PRN	Other pain treatm.	Impact on daily life acc. to w.s.
Jonah	yes	yes	yes	little
Boaz	yes	yes	yes	some
Joseph	yes	yes (seldom)	yes	little
Martha	yes	yes	no (does not want	much
Maria	yes	yes	no	very much, much
Rachel	yes	yes	no	very much, much, some
Matthew	no	no	no	little
Leah	no	yes	yes	little
Andrew	yes	yes	yes	much
Isaac	no	yes	yes	little
Jacob	yes	no	no	some
Sara	yes	yes	no	very much
	9 co-res.	10 co-res.	6 co-res.	
	3 co-res.	2 co-res.	6 co-res.	

Table 4.c. Self-description of co-researchers of the intensity of the pain

*	*	*	*	*	*
No pain	Mild pain	Moderate pain	Severe pain	Very severe pain	Worst possible pain
		Jonah			
		Boaz			
	Joseph	Joseph*			
		Isac		Martha	
		Maria	Maria		
		Jacob	Rachel		
		Matthew			
		Leah			
			Andrew	Sara	

Table 4.d. Assessment of the ward sister on the influence of the participants pain and discomfort on daily living.

Question: How much influence on the participant's activities of daily living do you think this pain and discomfort has? Ward sister:

no _____ little _____ moderate _____ much _____ very much _____

Jonah				
	Boaz			
Joseph		Martha		
		Maria*	Maria	
Isaac				
	Rachel		Rachel*	
Matthew				
Leah	Jacob	Andrew	Sara	

* Two different foci of pain with different intensity, when the names are mentioned more than once.

Table 4.e.

Overriding theme, major themes and subthemes

Unacknowledged afflictions: The essentials of the experience of people with persistent pain in nursing homes					
Reconciliation to losses in life	The lived experience of persistent pain				
Loosing loved ones Losing health and home Negative attitudes to old age Peace and reflection	All under control	Seeks help when needed		Reluctant to seek help	
	Set amount of medicine	<i>Receives help and care of doctors and/or nurses</i>	<i>Seeks help in vain</i>	<u>Attitudes:</u> Resignation to pain Personal ignorance Culture of never complaining	<u>Feelings:</u> Fear of a negative attitude of staff Lack of trust in doctors and/or nurses

Chapter five

Presentation of findings

5.1. Introduction

The purpose of this study was to get to know the lived experience of elderly people with persistent pain that were residents in nursing homes. In this chapter I will introduce the responses of my co-researchers in our dialogues. The findings will be set up according to the essential structure of the phenomenon under study as it is constructed from all the cases according to the Vancouver school of doing phenomenology (Chapter 4.7.). The research question was: **‘What are the essentials of the experience of people with persistent pain in nursing homes’?**

Having in mind that the mean age of my co-researchers was 86 years, I felt they needed some time to think about the question beforehand. Therefore, I introduced the matter for discussion usually the day before for each co-researcher. I told them I was interested in knowing what it was like to live in a nursing home with the status of health they have.

The following findings describe the essentials of the experience of my co-researchers. They told about different losses in life together with the lived experience of having persistent pain in a nursing home and also different sources of strength and joy. Added to this is my interpretation according to the method of the Vancouver school. It must be reiterated here that these findings should not be extrapolated to old people in nursing homes overall but looked upon as valuable insights into the lives of my twelve co-researchers, which hopefully after my analysis will open up a new understanding of this life situation.

At the end of Chapter four there is a table of the themes (Table 4.e.). The overriding theme is **‘unacknowledged afflictions: the essentials of the experience of people with persistent pain in nursing homes.**

Three major themes emerged from the data: **Reconciliation to losses in life, lived experience of persistent pain and sources of strength and joy.** Valuable insight was gained into the reactions of the old people to different former losses in life. Most of them seemed to show a stoic peace towards afflictions, as well as towards old age and diminishing health. A continuing of reconciliation to loss and pain and to unavoidable changes of old age seems to be going on. They also described present sources of strength and joy, which were most often their close relatives.

Their reaction to pain seemed to be twofold. While some people are content in spite of pain and seek help when needed, others show reluctance to seek needed help of different reasons and seem to tolerate their afflictions without recognition, unacknowledged. The reaction of staff to the complaints of the older people was thought provoking. While a majority of these residents received interest and management of their pain, a few seemed to meet considerable difference and even total passivity towards.

5.2. Reconciliation to losses in life

5.2.1. Losing and grieving loved ones

Becoming reconciled to the losses of a loved one, formerly in life or recently, seemed to be an ongoing work for most of my co-researchers. Interestingly, they chose to give an overview of their lives in the light of their losses. They often told about where they were born sometimes-memorable events from youth, told about their husband or wife and how many children. After that they usually started telling about the death of loved ones, accidents, even those that happened when they were young or some similar major experiences.

I never asked direct questions concerning these things, though. Some seemed to have worked through their grief while others were still in the midst of it or even bitter and angry. Is it not unusual that people in this age have lost not only a husband or a wife but also an adult daughter or a son. The loss of loved ones by accident or diseases are well known to them. Many of these old people described dramatic losses from childhood or their adult years in a few well-chosen words, giving me a glimpse into a world of hardships usually unknown to younger people. In our country the sea has taken its toll of seamen's lives at all times and in the first decades of the twentieth century, when most of my co-researchers were born, poverty and hardships were common in different places in the country. In retrospect I believe my co-researchers were situated in different places along the line of adjustment to pain from little reconciliation, or even anger, towards full agreement and reconciliation.

Andrew, the first co-researcher I introduce a lively man with a vivid memory and good ability to express himself. He has a room of his own and can walk with the help of his rollator. His father drowned when he was a little boy. Later in life he himself lost his beloved wife leaving him with four children to take care of. Repeatedly he described how he tried his best to be both a father and a mother to his children:

... the boat went under with everything in it, one piece from the boat was found in the sea, no more. I was only two years of age.... Well, life was like that when I grew up. My mother got married again.... And I felt, you see, that after I lost my wife, - that I needed to be close by my children ...

Andrew moved his place of work close to his home. He also expresses joy and pride when he talks about his children how he managed to bring them up and how they finished their higher education one after another.

Jacob is blind but he still can get about carefully with the help of his rollator. He is one of my oldest co-researchers. Many years ago he lived in an apartment in a flat in an old people's home together with his wife, and describes to me how

good that time in his life was and maybe the best in their marriage. When she died Jacob soon had to move to a nursing ward. He tells me that when she died his life 'fell to pieces' and means that he lost control of alcohol and other things after her death.

Seven of my co-researchers had lost their husbands or wives. All except one told me about that especially. Another old man, Matthew, had become a widower only two months ago. Matthew is a tall man a little hesitant in his manner and has started to forget a little. He also had had to move to a nursing ward after she died. He was a man of few words but whenever he mentioned her he added how many children they had had together, and they were many. It was as if he was expressing how much she meant for him, and how he missed her. In fact I think he was in much grief at the time of our dialogues.

Maria is a thin woman with a low voice. Her simple but startling story is one of a girl with a difficult childhood of poverty and parental abandonment. Her life as an adult was replete with painful losses and grief. She generously but simply told her story:

I was adopted when I was one and a half years old by an elderly couple, good people. I was there until I was ten, then he died [her foster father], and I had to work for my food and clothing until confirmation. My father and my mother were so poor.... They were bringing up John, my brother...they lived together [in the village by the sea] but I could not be added to that group, there was nothing to eat....[Later:] I lost my husband, the father of these six children. The girl was nine months of age then. I gave her up to be adopted, but that turned out to be a rather bad home. Then I lost two of my sons. One was eighteen years of age. He drowned. The other.... disappeared..., you see. Then after maybe a month he was found just like that in the harbour. (Silence) I could never see the body.

Later Maria tells me how she has learned to react to loss and pain. She hinted in the direction that adversity is something a person should gain from and grow with. She seems to have found meaning in her afflictions. Once she said that

difficulties are supposed to 'be good for you' and means that such afflictions bear with it the possibility to grow as a person. I sense in this woman both a low self-image possibly from childhood but also pride when she tells about her children and things she has accomplished in life in spite of poverty and extreme difficulties.

5.2.2. Loosing health and home

Secondly, the transition to leave their own established home and be admitted to an old people's home seemed a major step for my co-researchers, although a few were relieved to finally get much-needed service when it had become absolutely necessary. They seemed to see it as a big step downward towards dependency on others and loss of freedom, at least before they made the move. Many were quite content when they had become acquainted with life within the nursing home. Although these adjustments often went well they missed their former home quite a lot. So, the loss of their former home and together with it a new dependence upon others was another change of old age to become reconciled to.

Usually going straight into a nursing ward happened only if my co-researchers came right from a hospital. For those in the old people's home, finally going to the nursing ward when their health had further deteriorated sometimes was experienced as another major step towards more dependency on others.

Joseph has had Parkinsonism for many years. He came to the nursing home only a few years ago right from his home. He is one of my youngest co-researchers, a little bit over seventy years of age. His wife lived in their home. He missed his home very much. He can seldom go there for a visit since his wife has back problems and does not trust herself to take him home alone.

Yes, I have always thought that there would appear something new that would be to cure this, but by now I have stopped thinking about it.... I realise I will be

here [hesitates] uncertain amount of time. [I ask if he feels he has become reconciled with this situation]. Oh, yes, I have.

On a closer look at the words he uses it might appear that he is somewhat annoyed at his wife for not trying harder because twice he uses the words ‘she doesn’t bother to take me home’.... At the same time he is happy that his children take him out for a ride once in a while. In spite of enjoying physical exercises and having a good fellow resident in the room, Joseph misses his home very much. I asked Joseph how he experiences life:

.... It is terribly monotonous. You’re dependent on others if you’re going anywhere. But my children often come to take me with them for a drive.

Leah, on the other hand, a small, low-voiced and careful lady was very relieved to get a permanent place fit for her after a time in hospital because of her hip fracture at home. She felt she had escaped some degree of social isolation when finally she left from the hospital for the old people’s home.

...Then I was so happy to be able to join other people.... At that time I was not sick either, only my leg bothering me.

During the first years, Leah was active in the social life in the old people’s home. But as the health deteriorated she told me how she loved to be in the quietness of her room. When she was allowed to stop going to the noisy dining room, as she described it, and have her food carried into her room, she was very grateful and said she felt at home again. Another co-researcher used similar words on the quietness. There seems to come a time for some of them when peace and quietness is appreciated over activities and social life.

The story of Martha was somewhat special because she experienced strongly that she was pressured by her family to leave home and accept a room in an old people’s home some years ago. Martha is a small, lively lady and seems to have a vivid memory and no obvious signs of dementia. She shares a room with another old lady. Martha can socialise with many of the staff like the nursing assistants and cleaning ladies and talks warmly about them. Very few of her

fellow-residents are able to keep any conversation. Some of the residents are restlessly walking around in the corridor, one of them is gesturing in the air as if he is angry but most are quiet or look sleepy sitting in their wheelchairs. Later I learn that Martha is sometimes afraid that one such man will make her fall while walking in the corridor with her rollator, which she knows she would not be able to handle, due to her imbalance.

Marta was very unhappy when she told me how she was made to leave her former home and move to an old people's home. Her flat was on two stores. She perceived that her family pressurised her very much to move into an old people's home. Once she was in there she got her own room and had some good years taking for example an active part in social activities and physical exercises.

Once she had to go to a hospital for a few days. When she came back the doctor and some others had decided that she would have to move into this nursing ward, since, as she perceived it: 'then suddenly somebody, a woman, proposedly had to get my place'. She is still angry because of this move and has put the blame on the doctor, presently is her only doctor. She says she does not trust that person and seems not to seek any medical attention to him.

This is what Martha first of all tells me in our dialogue and explains how hard it has been to be reconciled with this. She vaguely expresses that now she has done that, though. The nurses told me Martha once had a possibility to move to another ward but did not take that offer.

5.2.3. Negative attitude towards old age

What are the attitudes my co-researchers themselves have towards old age? What did they expect? Some of them talked about accepting the fact, that you couldn't ask too much of your relatives. Others were very grateful for everything done for them. Most exhibited the typical calm of the elderly who look back satisfied after a long life. This will be discussed in 5.2.4. Examples of some attitudes of my co-researchers, are: acceptance and stoic peace or 'taking things as they are'. Negative attitudes towards old age in individuals, groups or society as a whole has been called ageism. The last one will be discussed more in 5.4.3.

Different attitudes and especially ageism can be of importance in this connection. The well-known attitude of some old people that pain and old age inevitably go together can seemingly be a block to good pain management. Passivity without a reason can make the old person reluctant to seek help.

Andrew seems to have good connections with his children. He told me that his children visit him every 'once in a while'. He uses a part of a poem to express himself. It seems he would like to see his children more often. He seems to be expressing that he feels laid aside in a sense:

...I feel amazingly well. My kids visit me every once in a while... All of them work outside home and... you can't expect them to be here every day to pat this old man who is here *'banished from everyone, I lay down by the mountains'* as the old man said. That's the way it is now. You must not be too demanding.

Jonah, a low-voice cautious man who lived alone in a flat on the third floor in a beautiful part of town. He contracted Parkinsonism and finally had to go to a nursing home right after hospital when he could not get up from his bed any more. He shows this determinism, taking things, as they are, an attitude I often came across. Jonah had been in this nursing home for two years when he made a decision:

I realised I would not be able to move home again so I sold my flat last summer...you always regret it of course...The flat was bright and good, on the third floor ... a good view from there. [Resolved] There was nothing else to do but to take things as they are.

Maria, the one who had lost her two adult sons, seemed to connect old age with the disinterest of doctors and not without reason, it seemed. She had an unusual story to tell. A few weeks ago she had been sick and she felt unusually weak and thought herself she was starting to come down with flu. She asked for a doctor. No doctor came although a doctor visits the ward daily, and there were no

messages. She was still not well at the time of our dialogue. She repeated this story to me two times and once added these words as an explanation:

I once asked him [the doctor] to come to me - but he did not come.
[Added as explanation] We are old people.

5.2.4. Peace and reflection

Through the different narratives of deaths and accidents, grief, sorrow and joyful events, the heaped-up experience of one long life after another shines through. People look over a long life and they are reconciled to themselves and to their God. It seems this older generation had got ample opportunity to learn to adjust to the ultimate realities of life. It has been pointed out that an average person from middle age on has to face the death of elderly relatives, one after another as well as of some people their same age.

Maria gives a glimpse on her attitude on life and death. She seems to me an intelligent woman; a person of few words as many of my co-researchers. She describes how the hardships in life have quieted her down.

. then he drowned,- my husband. There was nothing wrong with the weather, only when it is supposed to happen, it happens. This was the first fishing tour in February.... I took everything as it came.
...I was very noisy when I was young, oh yes- all this makes you more quiet.

Leah was rather weak and did not feel well when I came for our second dialogue. The doctor had just been with her and she was somewhat worried, did not understand why he was not more eager to treat her constipation, and felt she was

denied some laxatives. She also had much pain in her abdomen. The nurses had told me on the way to Lea's room that she worried too much about her colon.

I was asking for some pills for pain a while ago, if I will get them or not. By now there are others- now the evening shift has arrived. I haven't had an answer yet about the pills. Oh well, that's how it is. Nothing you can do about it. You have to take it as it comes. One has become old, too – can expect everything.

5.3. The lived experience of persistent pain

The discussion of present health came later usually, after my co-researchers had given an overview of their life in terms of their losses and their still living loved ones. I usually had to inquire especially about the present pain, or they told me following the use of the pain map.

By professional help here means help of a registered nurse or a doctor. These professions are in charge of the nursing and medical care and they are responsible for assessing nursing needs and medical diagnosis, including pain management. In these nursing homes, enrolled nurses and nursing assistants saw to most of the daily bedside care under the supervision of registered nurses. The registered nurses (I call them nurses here) took care of the medication, the more complicated nursing interventions and contact with the doctors. On a daily basis, however, doctors usually contacted the resident only if requested by the registered nurse.

5.3.1. All under control

The goal of living without pain is not always realistic as old people usually realise well. Sometimes people can be content and active living with some measure of pain or discomforts that cannot be treated completely. Many of

my co-researchers were content with the management of pain they presently had and felt everything was under control. Joseph was one of them:

.....I need to have my medication every two hours.....to be in order. I get it at eight o'clock, ten o'clock, twelve, two...I do not feel these discomforts when this is in order.

Interestingly I found on a few occasions some kind of trust in the original set amount pills. People counted them every time, knew their size, colour and shape by heart. It was if everything was in order as long as the set amount of pills arrived, it seemed. When asked what they did about their pain, some of my co-researchers referred to the set number of pills they received regularly. It seemed for some that these different tablets were an assurance that something was being done for them, their hope possibly. They seemed to assume that the original set amount of medicine was not to be changed. Matthew for example thought that he was getting some medicine for his pain, but according to information from the ward sister that was not the case. Matthew unfortunately, was one of those that didn't express his pain.

Matthew: I don't know what these tablets they give me...a few times a day, or two or three times...what is in them...This is the medicine they give me and I don't know what it is for. There is pain medication in it.

It was similar with Andrew:

I think I have some medication because of my foot. [Cheerfully] I just consume this dear, and let the dice fall when they may, as they said in the old days.

This attitude towards pills, both ignorance and too much faith in a set amount, deserves more inspection, since it might present one obstacle to quality pain management since one component of good pain management is constantly adjusting it to the perceived need. It can possibly give only false hope if pain management is not effective. Another side of this issue is possibly too cautious use of medication. On the other hand can too much fear of medicine,

especially narcotics possibly be a hindrance. I did not directly find that in my co-researchers, however.

5.3.2. Seeks help when needed

Most of my co-researchers were willing to seek professional help to ease their pain when needed and actively did so. Some would ask for the doctor, some asked the 'girls' to let the nurses know. There was active response from the doctors and nurses in most cases, according to my co-researchers, i.e., there was no problem with the response of staff whenever someone needed help. Sometimes a medical examination was done, sometimes a PRN medicine administered. Physiotherapy was active in half of my co-researchers. Still, nursing procedures on the ward other than medicine were never mentioned in our dialogues, e.g. hot pads or massage. The majority of my co-researchers felt they received adequate pain management, it seems. However, there were disturbing exceptions to this rule, that I will discuss later.

5.3.2.a. Receives help and care of doctors and/or nurses

Andrew and Sara are examples of this. Andrew was asked if he had sought help from a doctor because of his problems.

Oh, yes, there are good doctors here, I think. He examined me carefully the other day; I don't remember his name, a young doctor.

Sara is a very thin, small lady seemingly suffering from osteoporosis. Her pain has been very severe. She has other sources of pain, too. Although she talks, as the doctors do not quite believe her, she is happy with this new medicine. Just recently Sara at last got some relief from her severe backache when she started to get some narcotics.

.... they always give me something for it, if possible and there is something to be found for it. I think it is the best, or has been.... I got the newest one, according to doctor NN... some kind of a sticking plaster they put on me...if it is because of that or what, at least it works.

5.3.2.b. Seeks help in vain

As mentioned before, Maria had a different story. She had moved to the nursing ward a few months ago. She perceived direct neglect from her doctor, there. A few weeks ago, she had asked for a doctor. She felt very weak at that time. She felt there was no response whatsoever to her asking for medical help. No doctor visited her. These problems were connected with her daily pain, though. She also said that her main health problems had not got any medical examination for years. I asked what the doctor had said to her about her problems.

Maria: I have not seen any doctor here. I was going to get a doctor the other day, I was so weak but he never came. Maybe they don't get a doctor if such an old woman is sick.... I don't know if it is my fault.

It is worth noticing that she wonders if the fact that the doctor does not come is possibly her fault. It seems to me this affects her self-image quite negatively.

5.3.3. Reluctance to seek help- attitudes

There are those that have a somewhat passive attitude or show indifference. They even try for some reason to hide their discomfort from doctors and nurses. Three or more of my co-researchers seemed to react in this way. All of them seemed to be in considerable pain. What could be their reasons for this reaction? Two of them seemed in some way to have resigned them to pain and discomfort and one co-researcher called it pride the habit of never complaining.

5.3.3.a.1. Resignation to pain

What does "old age" mean to my co-researchers? Some of my co-researchers talked as if incurable pain and old age inevitably go together. There is a glimpse

of hopelessness in this view and such attitudes could easily effective pain management.

Sara vividly describes the experience of living with quite intense chronic pain in the nursing home. She is a small, determined woman with a little ironic sense of humour. She herself describes the intensity of her pain as very severe and the ward sister describes it the same way.

No, there is a difference in feeling some pain or having intolerable pain the whole day, but the worst is when I have this pain, that it drains me of all strength, I lose all my willpower...it is as if the pain takes control...

5.3.3.a.2. Personal ignorance

Some of my co-researchers seem to lack information or is maybe ignorance, another way of resignation? Jacob seemed very unknowing of the situations in the nursing home. He is almost blind but he still can get carefully about with the help of his rollator. He has pain in different joints and sometimes in the abdomen. He does not seem to be well oriented to his nursing ward. I ask him if he has thought of seeking help of doctors when he has the worst pain.

Jacob: No, no, no. No other doctors than those that drew out my teeth [many years ago]. There are no doctors around here...

Me:...do you not think you can be helped concerning your health?

Jacob: No, no. My dear, let me tell you, I am so old. I can't have more than two or three years to live, than I am one hundred years old.

Here is seems to be the attitude of this old man that he is too old for doctors, at least for this chronic pain he has. It must be remembered that there are side effects of chronic pain that goes untreated, e.g. immobilisation and lack of sleep. A nurse had the initiative to offer Jacob analgesics in the evening, which worked well.

Both doctors and nurses were working on Jacob's ward, which was similar to other nursing wards. The nurses gave him medicine 2-3 times a day. However,

there were no traditional doctors round. The doctors usually only came to the resident on request. In our dialogue Jacob claims: '...I don't talk to any doctor, they are not around here'... Then he remembers one that visited him recently and examined him well. I ask if he has some interaction with the nurses.

..one has no connection with them. I think the ['girls'] always keep in contact with them, it seems so to me. I presume they are nurses those that come here every now and then.

5.3.3.a.3. Culture of never complaining

Martha's pain seemed to be multifocal and quite intense at times. She herself described it as very severe pain and the ward sister as much pain. When asked if she often had to ask for analgesics, she replied with determination and laughing gently: 'No, no, no. I do not do that'! When asked why she said:

Martha: 'I don't know. Maybe it is my pride...I try to get along without it. Me.: Have you thought about whether there is something you yourself would like to do to lessen the pain, which is maybe not possible to do here?

Martha: I don't know- I think that would be very difficult. ...I just do as they tell me [the registered nurses]...I mainly talk to the 'girls'.

Later Martha was asked if she told the nurses about her pain and discomfort.

No, no, no, I don't complain...I don't complain like that without a reason. I am quite sure too, I know, that they think I am much better off than I am. They don't know those dear people. Me: 'What do you do then when you feel so much discomfort, what do you do to be able to live with it'? Martha: 'I just lie down or something'.

5.3.3. Reluctance to seek help-feelings

Different feelings can be a part of the experience of pain. Possibly this is connected to the silencing effect of pain. You have to depend on others to believe what you say. Among my co-researchers I found fear of meeting a negative attitude, lack of trust and different kinds of ambivalence together with a low self-image of the pain victims.

5.3.3.b.1. Fear of negative attitude of staff

Matthew was very reluctant to express his pain for the doctors or nurses. He did not receive any medication for his growing pain in both knees, although he himself thought he did. What about the perceived attitude of the staff as seen by the co-researchers. Is it possible that there is a reason for such fear?

Matthew: I was going to talk to him when he came. I felt he was somehow a little ...against it [laughs with embarrassment] or something- I don't know, I don't know'.

5.3.3.b.2. Lack of trust in doctors and/or nurses

Martha was mentioned before in the connection of not trusting the doctor. Matthew also at one time seems to be expressing that he does not really trust his doctors. I once ask him why he does not seek the doctors for his pain. He answers: ... it is maybe that you don't believe enough in them [the doctors]...

5.4. Sources of strength and joy

In spite of different afflictions there are also sources of strength and joy among those with persistent pain in the nursing home. The joy and fulfilment of those that had regular visits of loved ones was very evident. Good conditions of living made life understandably easier and reasonable health was of core importance. It

was also noticeable how some co-researchers were happy with physical exercises, especially the men. On the other hand two ladies had talked about how they enjoyed the quietness in their rooms.

5.4.1. Adhering to a family

In the midst of new challenges some definite sources of strength were evident. Visits from loved ones seemed to be the greatest source of strength, joy and personal fulfilment for many of my co-researchers. Similarly, some token of being cared for, being precious counted for the same. Martha had regular and frequent visits by her daughters. They sometimes took her in a wheelchair out of the ward for a sightseeing trip around the building. She never went anywhere without them. By then she never went out of the ward unless one of them was with her, although the staff were willing to escort her.

Sylvia is my pillar of support. Poor Sylvia would have taken me if I had wanted [to a party in the hall]. She is a great support to me.

Rachel, a radiant and charming lady with good ability to express herself told me about her two daughters both of who were living far away but were still very closely connected to her.

Rachel [proudly] ...and my daughter calls to me every Saturday. She is married now in ... and lives in a good marriage and they have no children together.There is a lot of love between us, a lot of love.

This seemingly gave Rachel self-fulfilment and joy. Maybe this is a source of strong self-image.

Doing well to another resident seemed to be a source of genuine fulfilment and joy to some of my co-researchers, too. Martha, who found herself in the midst of difficult circumstances, spoke so nicely of the old lady that shared a room with

her. Similarly Andrew spoke with much understanding about the old neighbour who was so noisy that Andrew had to take sleeping pills for a while.

In contrast, one of my co-researchers had not seen his children or grandchildren for decades. He talked openly about old different mistakes, like the use of alcohol, which had contributed to this situation. He seemed lonely.

5.4.2. Reasonable health and good conditions of living

The majority of my co-researchers were content and grateful for the life and situation within their nursing homes. Two other factors, reasonable health and good living conditions seemingly were another important source of strength for those who had that. Similarly, when the living conditions were not good it was very tiring, like being irritated of another person's behaviour.

Boas, a slightly disabled man who lived his whole life with his brother and his family, how he had experienced moving into a nursing home:

Yes, I was a little nervous in the beginning because I hadn't even entered a place like this before.... But you are quick to become acquainted and as I said- this is top people [the staff]...but there is one disadvantage, though. The food is far too good, you get far too fat, you have to restrain yourself, you see...'

Isaac: a diabetic, who had lost both his legs, had come to this nursing home one year before.

It is very good to be here, especially after I moved down here into a single room. I was in a double room before that, which was very different, you never know who comes next. It is much better to be alone, a private toilette and all you need.

Rachel gives the 'girls' a beautiful testimony. She says:

There are no better girls anywhere to help a person. They understand so well how things are for these people.

5.4.3. Physical activities and exercises

Especially among the men did I find joy and fulfilment in taking part in physical exercises alone or in a group. Jacob loved doing gymnastics, Andrew wanted to work more at the physiotherapy than he was allowed to, and one co-researcher loved going out in the sun and staying there the whole day in his wheelchair. Such activities possibly are a token of hope, of being able to keep the health considerably good. All these enjoyable events gave rays of sunshine into the days of old age in the nursing home.

5.5. Summary

In this chapter I have explained the major themes and subthemes as analysed and interpreted from the dialogues with my co-researchers. The major themes were resignation to losses in life, the lived experience of persistent pain and sources of strength and joy. When my co-researchers were asked about pain, different losses of their long life first came to the fore. This seems to indicate that there is an ongoing work of reconciliation going on, reconciliation to different losses and inevitable changes of old age.

My co-researchers perceive the doctors and nurses mostly as performing active pain relieving measures. A few residents get little or no help for their pain. There seems to be a block in the pain management in their cases. It must be remembered though that what is described here is the perception of my co-researchers. However, in spite of afflictions there are some very evident sources of strength and joy in the lives of the residents which are mainly the visits of loved ones, reasonable health and good conditions of living.

Chapter six

Discussions

6.1. Introduction

In this final chapter I will discuss the findings in my study and their implications. First there is a short orientation of the aim of the study and the overall findings together with limitations of the study. Then I will highlight what seems to be new knowledge here, what is similar to former research. Nothing was found that seemed to be clearly different from former research. Lastly there are implications for professional practice and education and recommendation to future research.

6.2. Aim of the study and main findings

The aim of this study was to get a better understanding of the essentials of the experience of elderly people who have persistent pain and are residents in nursing homes, and of the possible meaning their pain and discomfort hold for them, hoping to obtain knowledge that might be of help for better pain assessment and effective pain management among this age group.

The overriding theme is ‘Unacknowledged afflictions ‘ and three major themes were found: reconciliation to losses in life, the lived experience of persistent pain with the subthemes of ‘ all under control’, ‘seeks help when needed’ and ‘reluctant to seek help’, and the third major theme was ‘sources of strength and joy’. (See table 4.e.on page 40).

6.3. Limitations of the study

This study is part of my master's education and is my first effort in research projects. The time limit, around 13 months, was quite tight for this type of work together with other obligations in workplace and home. These facts might influence the overall quality of the research to some extent. Since English is my second language it is possible that my expression is not always accurate.

6.4. What was surprising when compared with other research or literature

Pain in a wider perspective

Interestingly, most of my co-researchers responded to my inquiry on life in pain in the nursing home by giving me an overview of losses in their life. In this free expression of the dialogue type interview, they highlighted the death of loved ones, a spouse or a child, losses both from long ago as well as recent losses. I did not expect beforehand that they would connect these things so definitely to my question of present pain. In a similar way they told about the move from their former home into an old people's home or a nursing home. It seems to strike as one big loss of both home and independence although many of them had a good life once they were inside the nursing home. Possibly, the losses of life were used as kind of milestones to give an overview of their lives. No direct questions were asked that called for this response. Through these narratives it seemed that an ongoing work of reconciliation and adjustments to different losses and changes was going on. A few were bitter and angry, many were in the process of becoming reconciled to their share in life, and a few did show inner peace and reflection. It seemed there was a lot of inner work in process. Such work of reconciliation and adjustments might possibly influence health and well being.

This connection of loss and pain was somewhat new to me. In a recent article with the name *Old age, loss and pain* (2001), Roy describes a case study that illustrates loss and grieving, caregiver burden and other issues in a chronic pain

patient. He maintains that these stressors significantly affected pain management and coping. He concludes that common recognition and appropriate treatment of important issues of life like loss and grieving is important and since they are part of the bio psychosocial experience of chronic pain. Is it possible that there is an important connection between loss, healthy work of grief and reconciliation and less pain? Would some of my co-researchers have done better with a caring support in the light of their losses? I think of Martha who still grieves her son intensely it seems after more than thirty years. I think of Matthew who lost his wife a little over two months ago and seems lost in new surroundings with new staff and does not seek much needed help.

In an interesting article about alienation, suffering and chronic pain, Younger (1995) claims that suffering and chronic pain are related. A pain can become a suffering mainly for three reasons, the author says. It happens if the pain is chronic, if there are some fright connected with it and if the individual feels out of control.

Besides, pain, according to Younger, seems to isolate people in a certain way. First it isolates a person from self, 'me and that leg with the pain', and after that from others. Lastly, suffering makes one a stranger and there is a reaction of others to turn away from this stranger.

Some of my co-researchers definitely felt out of control in their chronic pain, at least from time to time, I believe, like Sara, Martha and Matthew. The latter two seemed to be quite isolated in their pain and their afflictions seemed unnoticed by staff. Certainly, Mary felt alienated, too, waiting for her doctor. According to Younger, in all suffering there seems to be a factor of psychosocial alienation.

In chapter 2.5.3. the silencing effect of pain is mentioned. That is a very interesting phenomenon, not the least for nurses. Younger claims that suffering, has certain ways of expression. Intense suffering starts with being mute, no words are found, maybe only groans. Next stage is an expressive suffering where there is a deep, urgent need to tell, to narrate about what happened. This step is very important. By this people seem to work on distancing themselves from the suffering. The last stage of Younger's expression of suffering is when the person finds an autonomous and authentic voice and the sufferer sees a ray of

hope of change. When I compare my finding with these, I realise that although not in acute suffering, my co-researchers did show a definite need to tell, narrate, about distressing things. They got a listener, which can be rather seldom experience in the rush of daily activities within the nursing home. A certain degree of alienation can be seen in their resignation to tell the staff about their bodily pain. One explanation of the stories of my co-researchers when they got a listener might possibly lie here. This can have implications for nursing since our clients might have important needs here they cannot express. Maybe it is not 'the way old people is', as often is said, to over and over tell about things from the past. Is it possibly a self-initiated therapy to work towards some kind of reconciliation to life?

The need of old people to reiterate things from their life, both good and sad things, is well known. Is this possibly a necessary developmental task? And if so, who is there to listen when our old residents need to speak. Buttler and Lewis (1977) maintain that it is the case and claim that failure to accomplish this task may result in psychological problems. So, possibly a developmental need became evident with my co-researchers when they got an opportunity to speak to somebody who had time. Here, again, I see the Vancouver school empowering for the co-researcher.

Losses are common in this age as can be seen with my sample. A major developmental task is to replace the losses with new relationships, new roles or the retraining of lost capacities according to Pfeiffer (1977). One or two co-researchers talked with much anger about the accidents that led to the death of a son or a daughter. Is here a possibly a chronic grief? According to Arnþórsdóttir (1998) chronic grief is when the bereaved cannot be reconciled with the loss even decades after it happened. He or she cannot get rid of feelings like anger, despair and shame in connection with his or her grief.

6.5. What was similar to other research or the literature

a) Passivity and resignation to pain

As mentioned before, a few of my co-researchers did not seek help for their discomforts. Somehow they seemed to have got resigned to their pain (Matthew, Martha), and lost hope for relief in some way. Others were reluctant to express their pain. One showed lack of knowledge of resources, or was it the indifference of resignation? Such resignation of elderly people is known from other studies and is clearly shown in the study of Yates et al. (1995). In their study, elderly people in long term residential setting in Australia seem to have become resigned to pain, they are both ambivalent about any action to relieve the pain and reluctant to express their pain.

In the study of Yong et al. (2001) some concepts come to the fore that sounds familiar. They designed a pain attitude questionnaire and administered it to 373 healthy community dwelling individuals and tested for age differences in stoicism and cautiousness. In short, they found age-related increase in three concepts: reticence, self-doubt and reluctance. In my study there were evidences of self-doubt (Matthew, Maria) and cautiousness (Matthew and possibly Jacob). The reluctance that came to the fore in my findings is well known from other research on pain (Yates et al. 1995).

This again raises questions: Why such resignation and hopelessness? How has such an attitude developed? Is it possible that society as a whole or even the health care staff has conveyed hopelessness or indifference to this generation? Or have the elderly themselves adopted such ideas. I believe the self-image of many elderly is fragile and needs strengthening and care. They are in a vulnerable situation in many ways. The negative attitude in society can be heavy to carry. In an institution, a 'burden to society' (when in fact they founded modern society and handed to us), not of much use any more. In chronic pain it is well known that the self-image becomes low. This I could see in my co-researchers Maria and Matthew who felt intimidated. What values do we convey to them? That they are invaluable as human beings right here and now? It might be important that health care staff to check their personal attitudes honestly once

and a while, since inner attitudes seem to have the tendency to come to the fore sooner or later.

b) Knowledge and attitudes of staff

Although only a minority, a few of my co-researchers seemed to dislike the attitude of the staff. One man among my co-researchers said he was afraid of the attitude he would get if he complained and a lady said she didn't trust the doctor (see table 4.e). But what is known of the knowledge and attitudes of staff? Some research have shown that although the majority of nurses have reasonable knowledge, a considerable amount of them still have old myths concerning pain relief and have not taken new knowledge in use in clinical work (Closs, 1996, McCaffery and Beebe 1989). The old resident deserves nothing less than a quality nursing management. 'The cornerstone of good pain management for elderly people (as for all pain sufferers) is to assess them thoroughly, believe what they say, take the necessary action(s) and monitor the outcome of those actions' (Closs 1994, p. 1079). We must, under all circumstances, take them as valid, when they express their pain. Quality pain management can increase overall health and quality of life considerably among this age group. I do not know if lack of knowledge or some old myths were evident among the staff in these nursing homes. Still the question rises: Why have some of my co-researchers resigned to pain and are reluctant to ask for help? Have they come against a negative attitude before? New and grounded knowledge that chases away prejudices and quickly enters practice is among the rights of our clients and one of ethical duties of nurses and doctors, I believe.

6.6. Interesting issues

There was nothing that I know of in the findings clearly contrary to other research, but I would like to mention two interesting components. Both of them could possibly be culture -related here in Iceland.

a) Possible cultural differences?

One co-researcher (Martha) said that she laughingly that she would never complain, she had never done that in life. This is an interesting answer. She also called it pride. In the literature there is some cultural difference evident in the expression of pain (Bates et al. 1997) where there was a comparison of New England patients with a prominent mind-body dualism worldview and Puerto Ricans with who shared a view of mind body integrating. In this setting, shared views and values contributed to more supportive patient-provider relationship. Here in Iceland we have the Saga's with many unforgettable narratives of pride in the face of hardships. The Vikings even said a poem after one leg had been cut off. I believe such pride is well known to this generation that has faced hardships unknown to younger generations. It would be worth examining that further.

b) Where were the nurses?

On the whole, my co-researchers seemed to have good relationships with the staff and vice versa. The 'girls' and the cleaning staff got good testimony. Interestingly, registered nurses and doctors seemed more distant to them, though but in a different way each group. The doctors were closely connected with pain management in their minds, although they were a little distant to them. A few doctors had disappointed them but their role was very clear, all the same. The

registered nurses, on the other hand, seemed strangely distant. They were closely connected with bringing the pills, but not much with pain management. Very few seemed to expect that the nurse could have some effect on the pain medication if need be, and only once a nurse was mentioned as the initiator of pain management. Again, this raises some questions. Do residents not sense a difference because of similar uniforms of these groups? Do registered nurses need to introduce their service especially to new clients? Are they not prominent in pain management on the ward? Or is it possible that no news is good news; i.e. that the nurses never disappoint them and do their work in silence? What is the image of the nurse in the eyes of the resident in the nursing home?

In the research of Thomas (2000), the nurses were virtually invisible in the narratives of the pain sufferers too. This is a strange omission that deserves more inspection. It might have to do with the image of nursing in the eyes of the client. Or do nurses not see themselves as active participants in pain management? In the light of the situation as described in the literature it is important for the nursing profession to get rid of old knowledge and myths and be active in interdisciplinary work on pain management.

6.7. Limitations and strengths

The frailty of some of my co-researchers might be a limitation. A few of them had started to forget a little and a few were actually in pain at the time of our dialogue. Verification was only possible in two instances, due to the time that lapsed from the dialogues. On the other hand, I went two times to most of my co-researchers, which I believe is strength. I also have considerable experience working among this age group.

6.8. Implications for professional practice and education

1. It seems therefore evident that there are considerable unacknowledged afflictions among our clients. There seems a definite need to seek out the sufferers, do systematic assessment in the nursing homes to find them. A reliable assessment tool is needed for this where attitudes, frailty and even dementia are taken into consideration. There are some tools being developed already. One of them is described in Axelsson et al. (2000) (See chapter 2.4.3.). That method gave promising results. This was a combination of an interview and observation of the resident's reactions during activity, together with physical examination. Almost half of this group had dementia. Still, they were able to identify pain in 88% of these people, only 49% had been treated with analgesics and with 27%, pain was documented in the nurse's daily notes. I believe this or similar tool could be recommended for systematic use of an interdisciplinary team of doctors, nurses and physiotherapists in nursing homes.

2. Nurses need to make an effort to take sooner into clinical use new knowledge on pain management and systematically discard old myths that prevent quality pain management. It seems that an educational thrust is necessary in this matter.

3. Nurses could examine their relationship building with the client and what attitudes they express. The client often is very sensitive and the person in chronic pain often needs extra care and encouragement. Under all circumstances the staff must take the description of the person on his or her pain as valid. The extra burden of prejudice from staff should not be tolerated (Thomas, 2000). Building a professional relationship of care towards the client is fundamental in our clinical work, I believe. Halldórsdóttir (1996) describes a nurturing theory of caring. She explains how good relationship- building towards the client is like building a bridge, symbolising openness and connectedness. I believe that the concepts of care and genuine respect for our clients are good guiding lights in clinical practice.

6.9. Recommendations for future research

Further research needed concerning the lived experience of loss for people in persistent pain and of a possible connection between loss, grieving and pain in old age. More accurate assessment tools need to be developed for the aged, both those cognitively intact and the cognitively impaired. Different biases in present assessment need careful consideration. More research would also be interesting on the possible cultural biases or blocks in pain assessment in our country.

6.10. Summary

In this chapter I have reminded of the aim of the study and reiterated the main findings in short. Some limitations were reiterated. It was surprising how my co-researchers seemed to see pain in a wider perspective, but resignation to pain and the importance of a caring attitude of staff is known from other research. Nurses seemed strangely invisible and there was an indication of a culture of never complaining publicly. Implications for professional practice and recommendations for further research were explained.

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Appendix I

To
The National Bioethics Committee,
(Vísindasiðanefnd of Iceland)
Laugavegur 103,
105 Reykjavík.

A request for ethics committee clearance.

Respected committee.

Hereby I seek your kind allowance for a research in nursing, due to be performed from September '00 to August '01. It is a part of my studies for MSc. degree at the Royal College of Nursing, University of Manchester, England. This educational program is by distance learning through the University of Akureyri, Faculty of Health Sciences. My Research Supervisor is professor Sigríður Halldórsdóttir, RN, MSN, PhD at the Faculty of Health Sciences at Akureyri.

Purpose: To inquire about the experience of residents/patients in nursing homes about their experience of pain and pain related discomfort. With that I hope to get some information that could possibly be of use to assess pain and manage it purposefully in this age group.

Relevance: It is a well known human experience that pain and discomfort, physical or psychological, tend to have comparatively much influence on overall well being of people. When, on the other hand, we get some relief from our pain, it often results in multiplication effects on health and well being to the better. Elderly people often have more than one kind of pain. These people are often frail, dependant upon help of others and must turn to health care personnel for help for relief of pain.

Knowledgeable pain assessment, pain-relief intervention and reassessment are of paramount importance for purposeful health care of this group of people.

At the same time, many authors have pointed out that there is an urgent need to manage better this aspect in the care of the elderly people (Farrell et al. 1996, McCaffery and Beebe 1989, Ferrell 1996, Coop 1993, Melding 1994). Interestingly, it seems there is little epidemiological data on pain in elderly people. Studies have found prevalence rates for pain in the elderly ranging from 30-83 %. In one study, 71% of residents in nursing homes complained of pain thereof 34% described having constant pain and 66% intermittent pain (Ferrell et al.1990). In Iceland, I have not yet found reliable epidemiological studies on pain.

Sample: I would like to find up to 12 residents in nursing homes that have some experience, new or old of pain and related discomfort within this setting and can easily communicate. To find those, I would seek co-operation of the registered nurses in charge of the respective wards.

Methodology: This is a phenomenological research, based on Heideggerian, hermeneutic influences. The data gathering method is deep interviews. The plan is to take one to two interviews with each participant 1-1 1/2 hours long. The data analysis method will be that of the Vancouver school of doing phenomenology.

Preparation: If I get your kind allowance, I will turn to 2-3 nursing homes in the Reykjavík area and ask the Directors of Nursing for allowance and co-operation. Last, but not least, I will write a letter to the prospective participants and inform them about the research and ask for their participation. It will be clearly pointed out that participation is voluntary. If they are positive, I will come to them, explain about what participation involves, that they have the right to quit anytime and that this will be anonymous and strictly confidential. Also, all data will be discarded after use.

Yours sincerely,

Guðrún Dóra Guðmannsdóttir, BSc.
Bæjargil 50, 210 Garðabæ.
S. 5550840

Document I

Til Vísindasiðanefndar,
Laugavegur 103,
105 Reykjavík.

Garðabær, 15. mars 2000

Heiðraða nefnd.

Ég leyfi mér hér með að sækja um leyfi til yðar, sbr. reglugerð um vísindarannsóknir á heilbrigðissviði, nr. 449, 4. júlí 1977, til að framkvæma þá rannsókn sem meðfylgjandi gögn lýsa. Eins og þar kemur fram er ég nemandi í Mastersnámi við Manchesterháskóla í Englandi. Þetta er fjarnám sem Háskólinn á Akureyri hefur milligöngu um að fá hingað til lands.

Ég hef lokið undirbúningsnámi í aðferðafræði. Hluti af því námi var að gera nokkuð ítarlega rannsóknaráætlun varðandi mína rannsókn og skrifa þau bréf sem leggja þarf fram til að sækja um leyfi Vísindasiðanefndar og leita eftir upplýstu samþykki þátttakenda. Ég leyfi mér að leggja þessi gögn fram á ensku, því þau voru unnin á því tungumáli, og treysti því að nefndin láti mig vita ef hún vill að gögnin verði þýdd.

Ég mun, ef leyfi yðar fæst, leita eftir þátttakendum í samráði við hjúkrunarstjórnendur, á nokkrum öldrunarstofnunum. Hef ég í huga minni stofnanir hér á Reykjavíkursvæðinu.

Í sýnishorni af bréfi til væntanlegra þáttakenda kemur fram til hvers er ætlast af þátttakendum og hvernig réttur þeirra og persónuvernd eu tryggð.

Varðandi styrki, þá hef ég fengið námsstyrk frá þeirri stofnun sem ég vinn við, Hrafnistu í Hafnarfirði. Einnig hef ég fengið rannsóknarstyrk frá Jólagjafasjóði Guðmundar Andréssonar, gullsmiðs, kr. 150.000,- kr.

Ég stend ein að þessari rannsókn en mun hafa ritara. Hún mun ekki hafa aðgang að raunverulegum nöfnum þátttakenda. Leiðbeinadi minn (research supervisor) verður próf. Sigríður Halldórsdóttir, Háskólanum á Akureyri, eins og fram kemur í meðfylgjandi gögnum.

Með virðingu,

Guðrún Dóra Guðmannsdóttir,
hjfr. BSc.
Bæjargili 50,
210 Garðabæ.

Meðfylgjandi:

Umsókn (á ensku) til Vísindasiðanefndar
rannsóknaráætlun,
bréf til væntanlegra þátttakenda
starfsferilsskrá mín.

APPENDIX II

Translated from the Icelandic

National Bioethics Committee

Prof. Sigríður Halldórsdóttir
The University in Akureyri
Thingvallstraeti 23
600 Akureyri
Iceland

Ref. No.: 00/030/AF

Reykjavik, 29 May 2000

Re: "The experience of pain and pain-related discomfort among residents in nursing homes"

At their meeting on 11/05/2000 the National Bioethics Committee discussed the application submitted by you and Guðrún Dóra Guðmannsdóttir concerning of the above research plan, as per your letter dated 15/03/2000. The research is the master's project of Guðrún Dóra Guðmannsdóttir and you are her course supervisor and at the same time the responsible party for the research, as per your e-mail of 28/03/2000. The members of the Committee have reviewed your application and in addition sought the opinion of a specialist. The research proposal is hereby approved by the National Bioethics Committee with consideration of the following:

1. From the point of view of protection of the person it is doubtful that the researcher should obtain the names of the possible participants immediately after the indication by the nursing staff / nurses. It would be more acceptable to have the nursing staff first investigate how the potential participants felt about the research, after they had received a letter of introduction from the researchers to read over, and then to let the researchers know whether those in question would give their consent to let the researcher contact them for further explanation and to obtain formal consent to participate. The researcher would then be given only the names of those individuals who had expressed an interest in receiving more information about the research.
2. Forms for informed consent – introduction, information sheet and approval form – must be presented to the Committee in the form in which they will be presented to the participants. Only one such sheet was submitted with the application and it was not clear whether this was an introductory sheet or an information sheet, and furthermore the sheet submitted was in English. The approval form to be signed by the participants was not submitted with the application.
3. On the present form (see "benefits, cost, payment") it is pointed out that there is no financial advantage to the researchers or the participants, but on the other hand there is no mention of any other advantage to the participants for taking part in the research nor any risk that may ensue to the participants.
4. The introductory sheet and the information sheet must make it clear that the decision to refuse to participate or to agree to participate in the research shall not lead to any consequences, whereas the present form gives this assurance only for the executives of the nursing home in question.
5. The introductory and information sheets must indicate name, residence, and phone number of the person responsible for the research.

The application will be reconsidered as soon as the requested information has been received.

Per pro The National Bioethics Committee, respectfully

Ingileif Jónsdóttir, Chair

Copy: Guðrún Dóra Guðmannsdóttir, nurse, Baejargili 50, 210 Gardabaer.

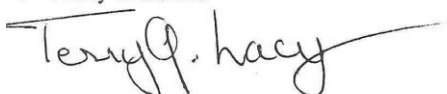
Translated from the Icelandic

25 November 2001

Terry G. Lacy, Ph.D.

Department of English (ret.)

University of Iceland

A handwritten signature in black ink, reading "Terry G. Lacy". The signature is written in a cursive style with a long horizontal stroke extending to the right.

DOCUMENT II

Sigríður Halldórsdóttir, prófessor
Háskólinn á Akureyri
Þingvallastræti 23
600 Akureyri

October, 29th of September 2000

To The National Bioethics Committee of Iceland
c/o Dr. Ingileif Jónsdóttir, Chairperson

Tilvísun: 00/030/AF

Reykjavík, 29. maí 2000.

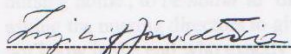
Varðar: "The experience of pain and pain related discomfort among residents in nursing homes".

Á fundi sínum 11.05.2000 fjallaði Vísindasiðanefnd um umsókn ykkar Guðrúnar Dóru Guðmannsdóttur vegna ofangreindrar rannsóknaráætlunar, sbr. bréf dagsett 15.03.2000. Rannsóknin er meistaraþrófsverkefni Guðrúnar Dóru og ert þú leiðbeinandi hennar í því námi og jafnframt ábyrgðarmaður rannsóknarinnar, sbr. tölvubréf þitt dags. 28.03.2000. Nefndarmenn fóru yfir umsóknina, auk þess sem leitað var álits sérfræðings. Rannsóknaráætlunin er samþykkt af Vísindasiðanefnd að teknu tilliti til neðangreindra athugasemda:

1. Út frá persónuverndarsjónarmiði orkar nokkuð tvímælis að rannsakandi fái nöfn hugsanlegra þátttakenda strax eftir ábendingu hjúkrunarstjórnað/hjúkrunarfræðinga. Eðlilegra væri að hjúkrunarstjórnaðendur könnuðu fyrst hug mögulegra þátttakenda til rannsóknarinnar, eftir að þeir hefðu fengið kynningarbréf frá rannsakanda til aflestrar, og létu rannsakendur síðan vita hvort viðkomandi gæfi leyfi sitt fyrir því að rannsakandi hefðu samband til frekari kynningar og til að afla formlegs samþykkis fyrir þátttöku. Rannsakandi fengi þannig aðeins nöfn þeirra einstaklinga sem lýst hefðu yfir vilja sínum til að fá frekari upplýsingar um rannsóknina.
2. Eyðublað vegna upplýsts samþykkis – kynningarblað, upplýsingablað og samþykkisfirlýsing - þurfa að berast nefndinni í því formi sem þau vera lögð fyrir þátttakendur. Aðeins eitt slíkt eyðublaði fylgdi umsókninni og var óljóst hvort þar væri um kynningarblað eða upplýsingablað að ræða, umrætt eyðublað var jafnframt skrifað á ensku. Eyðublað vegna upplýsts samþykkis þátttakenda (samþykkisfirlýsing) fylgdi ekki með umsókn.
3. Á núverandi eyðublaði (sjá "benefits, cost, payment") er tekið fram að ekki verði um fjárhagslegan ágóða að ræða fyrir rannsakendur eða þátttakendur en hinsvegar er ekki rætt um annan ávinning þátttakenda af því að taka þátt í rannsókninni né þau óþægindi eða þá áhættu sem þátttökunni kunna að fylgja.
4. Taka þyrfti skýrar fram á kynningar- og upplýsingablaðum að ákvörðun um að neita eða hætta þátttöku í rannsókninni hafi engar afleiðingar í för með sér en á núverandi eyðublaði er eingöngu vísað til stjórnaðra viðkomandi hjúkrunarstofnunar í þessu samhengi.
5. Á kynningar- og upplýsingablaðum þarf að tilgreina nafn, aðsetur og símanúmer ábyrgðarmanns rannsóknarinnar.

Umsóknin verður tekin fyrir að nýju um leið og umbeðin gögn hafa borist.

F.h. Vísindasiðanefndar, með kveðju


Ingileif Jónsdóttir, formaður

Afrit: Guðrún Dóra Guðmannsdóttir, hjúkrunarfræðingur, Bæjargili 50, 210 Garðabær.

VÍSINDASIÐANEFND
Laugavegi 103, 105 Reykjavík
sími 551-7100; fax 551-1444

Formaður: Dr. Ingileif Jónsdóttir
Starfsmaður: Þorvarður Arnason
thorvardur.arnason@vsn.stjr.is

Appendix III

Garðabær, 29th of September 2000

To The National Bioethics Committee of Iceland
C/o Dr. Ingileif Jónsdóttir, Chairperson
Laugavegur 103
105 Reykjavík

Subject: Information the committee asked for concerning a research on pain and discomforts of residents in nursing homes.

Hereby I send the further information the committee asked for in a letter from 29th of May 2000 concerning my proposal on a *væntanleg* research called: 'The Experience of Pain and Pain Related Discomfort Among Residents in Nursing Homes'. In a letter from 15th May 2000 I sought for ethical clearance to the committee.

I would like to thank the committee for your comments in the letter from 29th of May 2000.

Concerning your comment no. 1 that it could be (orki tvæímælis) that the researcher would get the names of possible participants right from the nursing directors, I will do as you ask for.

(I had had in mind that a relative(s) would get all information at the same time as the resident, and could ask me more and decide about the next step if the resident would need such support. I had planned that the nursing directors would not know in the end exactly who would decide to take part and who would not, because I considered that would lessen the possible incline of the resident to tell only that what is good for the nursing home, to *be hollur* to 'their Home. This I could possibly solve though by asking the nursing directors to give me a few more names than needed so they would not know in the end who exactly decided to participate.

Concerning comments 2-5. Hereby there are exemplars of forms exactly as I plan to distribute them, i.e. information sheet for nursing directors and both sheets of

introduction, information and of consent form to the resident. When revising them I had your comments in mind.

I have decided due to much work in my studies to *fresta* the research for six months. It will hopefully start in next September.

Respectfully,

Guðrún Dóra Guðmannsdóttir, nurse BSc.

Bæjargil 50, 210 Garðabær, Tel. 555-0840

E-mail: gdora@mmedia.is

Hjálagt:

A letter to nursing directors

A letter to prospective participants and consent form.

DOCUMENT III

Garðabær, 29. september 2000

Til Vísindasiðanefndar,
b/t Dr. Ingileif Jónsdóttir, formaður,
Laugavegur 103,
105 Reykjavík

Efni: Umbeðin gögn varðandi rannsókn um verki og vanlíðan íbúa á öldrunarstofnunum.

Hér með sendi ég þau gögn og frekari upplýsingar sem nefndin bað um í bréfi dags. 29. maí 2000, varðandi áætlun mína um væntanlega rannsókn sem ber heitið: "Hver er upplifun aldraðra á hjúkrunarheimilum af verkjum og óþægindum tengdum þeim?" Á ensku ber hún heitið: "The Experience of Pain and Pain Related Discomfort Among Residents in Nursing Homes". Sótti ég um leyfi til nefndarinnar í bréfi dags. þann 15. maí 2000.

Vil ég þakka ábendingar nefndarinnar, sem fram komu í svarbréfi hennar frá 29. maí síðastliðnum.

Varðandi athugasemd nr. 1 um að það orki nokkuð tvímælis að rannsakandi fái nöfn hugsanlegra þátttakenda strax frá hjúkrunarstjórnendum, þá mun ég fara að ábendingum ykkar í því efni.

(Ég hafði haft í huga að ættingi eða ættingjar fengju allar upplýsingar um rannsóknina jafnhliða aldraða einstaklingnum, gætu spurt mig nánar og ákveðið með framhaldið með hinum aldraða ef þess þyrfti með. Ég vildi síður að hjúkrunarstjórnendur vissu nákvæmlega hverjir ákveða að vera með og hverjir ekki, vegna þess að þá tel ég hættu á að hinn aldraði hafi tilhneigingu til að segja aðeins það sem er gott fyrir stofnunina, af hollustu við "sína" stofnun. Þetta gæti ég þó væntanalega leyst með því að hjúkrunarstjórnin gefi mér upp nöfn heldur fleiri einstaklinga en þarf sem eru fúsir til að fá frekari upplýsingar, en viti svo ekki nánar hverjir verða með þegar upp er staðið.)

Varðandi athugasemdir 2-5 þá eru hér meðfylgjandi eyðublað í því formi sem ég hafði hugsað mér að leggja þau fyrir þ.e. upplýsingablað fyrir hjúkrunarstjórnendur og bæði kynningarblað, upplýsingablað og samþykkyfirlýsing fyrir hinn aldraða einstakling, og hef ég þá m.a. ábendingar nefndarinnar í huga.

Ég hef ákveðið að fresta rannsókninni um hálft ár vegna anna í náminu, og mun hún væntanlega hefjast í september næstkomandi.

Með fyrirfram þökk,

Guðrún Dóra Guðmannsdóttir, hjúkrunarfræðingur
Bæjargili 50, 210 Garðabæ, s. 555-0840
E-mail: gdora@mmedia.is

Hjálagt:

Bréf sem sent verður til viðkomandi hjúkrunarforstjóra.
Bréf til væntanlegra þátttakenda ásamt samþykkisýfirlýsingu.

Translated from the Icelandic

APPENDIX IV

National Bioethics Committee

Prof. Sigríður Halldórsdóttir
The University in Akureyri
Thingvallastraeti 23
600 Akureyri
Iceland

Ref. No.: 00/030-S1

Reykjavík, 21 November 2000

Re: Research project "The experience of pain and pain-related discomfort among residents in nursing homes" – Reply to comments.

The National Bioethics Committee thank you for your reply of 29/09/2000 (received 05/10/2000) and signed by Guðrún Dóra Guðmannsdóttir in response to the comments previously sent regarding the above research proposal, as per the Committee's letter dated 29/05/2000. With the reply were enclosed new forms for obtaining informed consent. Your reply has been reviewed and is considered completely satisfactory.

The research project is hereby approved by The National Bioethics Committee.

Respectfully, per pro The National Bioethics Committee,

Thorvardur Árnason, Director

Copy: Guðrún Dóra Guðmannsdóttir, nurse, Baejargili 50, 210 Gardabaer

Translated from the Icelandic
25 November 2001
Department of English (ret.)
University of Iceland

Terry J. Lacy

Sigríður Halldórsdóttir, prófessor
Háskólinn á Akureyri
Þingvallastræti 23
600 Akureyri

Tilvísun: 00/030-S1

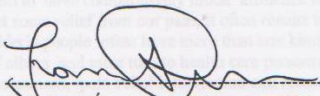
Reykjavík, 21. nóvember 2000.

Varðar: Rannsóknin "The experience of pain and pain related discomfort among residents in nursing homes"- Svör vegna athugasemda .

Vísindasiðanefnd þakkar svarbréf þitt, dags. 29.09.2000 (móttekið 05.10.2000) og undirritað af Guðrúnu Dóru Guðmannsdóttur, vegna áðursendra athugasemda við ofangreinda rannsóknaráætlun, sbr. bréf nefndarinnar dagsett 29.05.2000. Með svarbréfinu fylgdu ný eyðublað vegna óflunar á upplýstu samþykki. Farið hefur verið yfir svör þín og eru þau talin fullnægjandi.

Rannsóknin er endanlega samþykkt af Vísindasiðanefnd.

Virðingarfyllst, f.h. Vísindasiðanefndar,


Þorvarður Arnason, framkvæmdastjóri

Afrit: Guðrún Dóra Guðmannsdóttir, hjúkrunarfræðingur. Bæjargili 50, 210 Garðabær.

Appendix V

A request to interview selected residents in because of a research in nursing, on pain and pain related discomfort.

To:
The Nursing Director
of (nursing home).

My name is Guðrún Dóra Guðmannsdóttir, a BSc nurse. I have been working on geriatric nursing wards for around 10 years. The reason I write to you is that I will soon start a research programme on pain and pain-related discomforts among residents in nursing homes. I am doing my Masters degree from the University of Manchester, through the Faculty of Health sciences, Akureyri, and this research is a part of that programme. My research supervisor will be professor Sigríður Halldórsdóttir., Akureyri.

I would like to interview residents in your nursing home that have pain and/or pain related discomforts, or have had that before while in the nursing home. I am looking for people that can communicate, not cognitively intact. I am thinking of chronic pain of different origin. I would like to choose 5-7 residents in close co-operation with registered nurses or others that know the residents. If you grant this request, the plan is to write an informative letter to those people, and make a phone call a few days later. If they are willing to participate, I will visit them, give more information, and they will then sign a written consent. Very likely there will be two interviews around 1-2 hours long each. I try to make clear to the residents that the participation is absolutely voluntary, anonymous and full confidentiality is promised. Towards your nursing home the same is true.

Purpose: To inquire about the experience of residents/patients in nursing homes about their experience of pain and pain related discomfort. With that I hope to get some information that could possibly be of use to assess pain and manage it purposefully in this age group.

Relevance: It is a well known human experience that pain and discomfort, physical or psychological, tend to have comparatively much influence on overall well being of people. When, on the other hand, we get some relief from our pain, it often results in multiplication effects on health and well being to the better. Elderly people often have more than one kind of pain. These people are often frail, dependant upon help of others and must turn to health care personnel for help for relief of pain.

Knowledgeable pain assessment, pain-relief intervention and reassessment are of paramount importance for purposeful health care of this group of people.

At the same time, many authors have pointed out that there is an urgent need to manage better this aspect in the care of the elderly people (Farrell et al. 1996, McCaffery and Beebe 1989, Ferrell 1996, Coop 1993, Melding 1994). Interestingly, it seems there is little epidemiological data on pain in elderly people. Studies have found prevalence rates for pain in the elderly ranging from 30-83 %. In one study, 71% of residents in nursing homes complained of pain thereof 34% described having constant pain and 66% intermittent pain (Ferrell et al.1990). In Iceland, I have not yet found reliable epidemiological studies on pain.

Enclosed is a draft of the letter that the prospective participants will get. This research has been granted permission from the National Bioethics Committee, *Vísindasiðanefnd*. If you plan to grant me this request, I would like come and explain further the procedure and answer your questions.

Yours sincerely,

Guðrún Dóra Guðmannsdóttir, nurse
BSc.
Bæjargil 50, 210 Garðabær. Tel. 555-0840

Document V

Til hjúkrunarforstjóra
(nafn á viðkomandi hjúkrunaheimili)

Beiðni um að fá að ræða við nokkra íbúa vegna rannsóknar á reynslu aldraðra af verkjum.

Ég undirrituð hef unnið við öldrunarhjúkrun í um það bil 10 ár, og hef áhuga á að skoða nánar reynslu aldraðra á hjúkrunarheimilum af verkjum og óþægindum tengdum þeim.. Mun ég fljótlega hefja rannsóknarverkefni sem ber heitið:” Hver er upplifun aldraðra á hjúkrunarheimilum af verkjum og óþægindum tengdum þeim”. Þetta verkefni er hluti af námi mínu til MSc gráðu í hjúkrun frá Manchesterháskóla í Englandi, en það er kennt sem fjarnám frá Heilbrigðisdeild Háskólans á Akureyri. Leiðbeinandi minn við rannsóknina er Sigríður Halldórsdóttir BSc, MSc, PhD, prófessor á Akureyri. Rannsóknin hefur verið samþykkt af Vísindasiðanefnd.

Tilgangur: Hugmyndin er að taka viðtöl við nokkra einstaklinga (sennilega um 12 alls) sem allir hafa reynslu af langvinnum verkjum og óþægindum tengdum þeim, á þeim tíma sem þeir hafa dvalist á hjúkrunarheimili. Von mín er að fá einhverjar upplýsingar sem gætu hugsanlega komið að notum til að meta verki og meðhöndla þá á markvissan hátt hjá þessum aldurshópi.

Erindi þessa bréfs er annars vegar að biðja um leyfi til að taka viðtöl við u.þ.b. 5 einstaklinga sem búa á (nafn hjúkrunarheimilis). Ef leyfið verður veitt, langar mig að biðja um að hjúkrunarfræðingar sem vel þekkja til velji þessa einstaklinga í samræmi við lýsingu mína hér að neðan og leiti eftir því við viðkomandi íbúa hvort þeir vilji hugsanlega vera með. Sé viðkomandi jákvæður gagnvart því, þá myndi ég fljótlega hafa samband símleiðis við viðkomandi og mæla mér mót við hann (hana) og útskýra málið betur. Gjarnan mætti vera ættingi eða stuðningsaðili með á þeim fundi eða a.m.k. fá slíkur aðili aðgang að upplýsingunum sem hinn aldraði fær. Ef hinn aldraði samþykkir að vera með skrifar hann undir það. Mikilvægt er að hinn aldraði finni ekki fyrir neinum þrýstingi, enda er þátttaka í rannsókninni algerlega í sjálfsvald sett og vilji einhver ekki vera með eða hætta einhvern tíma í ferlinu er það algerlega frjálst.

Þátttakan felur síðan í sér að ég tek eitt viðtal við hinn aldraða um reynslu hans (hennar) í þessu efni. Áherslan er einkum á upplifun einstaklingsins og hvaða merkingu hann (hún) leggur í þessa reynslu. Dæmi: finnst viðkomandi t.d. að verkir eigi að fylgja ellinni og ekkert sé við því að gera. Þetta tæki ca 1-2 klst. Hugsanlega þyrfti ég að koma öðru sinni og spyrja nánar um einstök atriði. Það yrði sennilega styttri tími. Viðtölin verða tekin upp á segulband, en algjör trúnaðar gætt, og böndunum eytt að rannsókn lokinni. Í síðari umfjöllun um niðurstöður mun ekki verða hægt að greina einstaklinga né heldur stofnanir.

Hvernig þátttakendur: Er ég að leita að fólki sem getur tjáð sig að mestu óhindrað og hefur ekki við alvarlegar minnstruflanir að stríða. Um er að ræða króniska verki af ýmsum toga, þ.e. hafa staðið í 3 mánuði eða lengur, s.s. vegna slitgigtar, liðagigtar, eða gamala meiðsla; langvinna bakverki, jafnvel verki sem afleiðing af helftarlömum ofl. Þetta getur verið ný eða eldri reynsla en þó meðan viðkomandi var á hjúkrunarheimili.

Gildi slíkrar rannsóknar: Það er vel þekkt mannleg reynsla að verkir og önnur óþægindi, líkamleg eða sálræns eðlis, hafa mikil áhrif á almenna líðan fólks. Þegar hins vegar hægt er að létta einhverju af þessum óþægindum af, þá virðist það einnig bæta líðan og heilsu margfaldlega. Eldra fólk þjáist oft af fleiri en einni tegund verkja. Þetta fólk er oft veikburða fyrir og háð öðrum um hjálp. Það er einnig háð aðstoð heilbrigðisstarfsmanna við að minnka verki og vanlíðan. Vandað mat á verkjum, úrræði til að minnka verki og vanlíðan og síðan endurmat eru allt mikilvæg atriði í markvissri, faglegri umönnun þessa aldurshóps.

Margir fræðimenn hafa orðið til þess að benda á að nú sé mikil þörf á að standa betur að þessum þætti í umönnun aldraðra (Farrell et al. 1996, McCaffery and Beebe 1989, Ferrell 1996, Coop 1993, Melding 1994). Það virðast vera litlar upplýsingar um útbreiðslu verkja hjá öldruðum. Rannsóknir benda til að verkir séu áberandi í 30-83% tilfella. Í einni rannsókn frá Bandaríkjunum reyndust 71% íbúa hafa verki, þar af 34% stöðuga verki en 66% við og við (Ferrell et al. 1990). Hér á Íslandi hef ég ekki fundið áreiðanlegar rannsóknir á útbreiðslu verkja.

Vildi ég gjarnan hafa samband við þig símleiðis fljótlega og finna tíma til að koma og ræða þetta betur ef þér sýnist hægt að verða við þessari málaleitan. Vil ég fullvissa þig um að okkur sem að þessari rannsókn stöndum er mikið í mun að valda sem minnstum óþægindum fyrir þátttakendur.

Virðingarfyllt,

Guðrún Dóra Guðmannsdóttir, hjúkrunarfræðingur
Bæjargili 50, 210 Garðabæ
S. 555-0840

Appendix VI

(date)

Subject: A kind request to participate in a research.

Dear resident: (name)

I am a nurse and work in geriatric nursing. Last year I have been studying for a Masters degree in nursing from the University of Manchester in England. This is a distance learning programme, coming through the Faculty of Health Sciences in Akureyri.

The students in this programme are supposed to do a research on a subject they think is apt and will be of good use within nursing. In my job I have often seen how different experience of pain and pain related discomfort can make life difficult for the elderly people. Different measures of proper pain relief should be and often are tried, with the hope of giving the person better life. We still need to know more about how people experience this situation in their life. With this research, and help of people like you, I hope to add to this knowledge, so that pain assessment and intervention can become more effective in the nursing homes. My research supervisor will be professor Sigríður Halldórsdóttir, nurse.

The reason for this letter is that I would kindly like to ask you to participate in this research. Here below are further information on this project, and how it would concern you if you agree to help us.

The purpose of the research

To inquire about the experience of residents or patients in nursing homes about their experience of pain and pain related discomfort, and what effects does this experience has on them. By that I hope to get some information that could possibly be of use to assess pain and manage it purposefully in this age group.

Relevance

It is a well known human experience that pain and discomfort, physical or psychological, tend to have comparatively much influence on overall well being of people. When, on the other hand, we get some relief from our pain, it often results in multiplication effects on health and well being to the better. Elderly people often have more than one kind of pain. Some of them are frail, must depend on help from others and have to turn to health care personnel for help for relief of pain.

Knowledgeable pain assessment, pain-relief intervention and reassessment are of paramount importance for purposeful health care of this group of people. It is estimated that around two thirds of people in our nursing homes in Iceland have more or less pain. At the same time medicine and nursing claim that theoretically many of these people could get some relief from their pain if well managed.

Methods in this research

If you agree to take part in this research it will be done in the following way. I will take an interview with you about your experience of your pain and discomfort. It can be something you are experiencing now or before in life, but after you came to the nursing home. The interview will take 1-2 hours probably.

You have the right to stop the interview anytime, if you like. The interview will be put on a tape and written up so that I can better learn from it. Possibly, I will inquire more about some aspects of your talk later, so that I know I have understood you right. The tapes will be securely stored and the interviews will be kept anonymous. No one except me will know the real names of the participants and the tapes will be erased after use in this research. I will make a code that I will keep safe. I assure you of full confidentiality concerning what you might tell me. The staff of the Nursing home will not have any access of this information, either. In any reports or papers on this research it will not be possible to find out who the persons are or what nursing homes there are.

Benefits, cost, payment.

I will not benefit anything personally, financially, from undertaking this research. It is only part of my studies. I do not receive salary from anyone, but a research fund has granted me some money so that this is possible. The participants will not receive any payment, either.

This research has been granted permission from the National Bioethics Committee, *Vísindasiðanefnd*. I have also got the kind allowance of the management of the nursing home to interview some residents. I asked some of the nurses in your home to point out to me some residents that they knew were often in pain or had been that before. You are one of those.

I want to reiterate that taking part in my research is voluntary. If you decide not to participate or stop somewhere along the way, it will not have any consequences towards the management of the nursing home.

Within a week or so, I will call. If you have any questions right now you are welcome to call me. Maybe you would like to show this letter to relatives or that I inform them personally, that is fine. If you are willing to participate, we will find a convenient time and I will visit so that you can answer a few questions and sign a written consent. You can choose where you would like to be when we talk.

Hoping with you for a life in good health,

Guðrún Dóra Guðmannsdóttir, RN, BSc.

Tel. 555-0840

Document VI

Rannsókn um verki og vanlíðan meðal aldraðra Upplýsingablað

.....

Þakka þér fyrir að leyfa mér að kynna fyrir þér rannsóknina sem ég er að hefja um verki og vanlíðan meðal aldraðra.

Ég er hjúkrunarfræðingur og vinn við öldrunarhjúkrun. Síðastliðin tvö ár hef ég verið í framhaldsnámi í hjúkrun til meistaraþráðu við Háskólann í Manchester í Englandi. Þetta er fjarnám gegnum Háskólann á Akureyri. Meðan á náminu stendur er ætlast til að nemendurnir geri rannsókn á einhverjum þætti hjúkrunar sem þeim finnst mikilvægur og þar sem talið er að aukin vitneskja geti komið að gagni fyrir hjúkrun í landinu.

Ýmiss konar verkir og óþægindi tengd þeim eru nokkuð algeng á efri árum. Sem betur fer finnast oft ýmis úrræði sem dregið geta úr verkjum og gefið betri heilsu. En meiri vitneskja þyrfti að vera til um það hvernig fólk upplifir langvarandi verki á þessu tímaskeiði lífs síns.

Inni á hjúkrunarheimilum er það að miklu leyti verkefni hjúkrunarfræðinga að meta verki og beita úrræðum til að draga úr þeim. Þess vegna hef ég áhuga á að tala við fólk sem býr þar. Ég vonast til að þessi rannsókn geti verið framlag í þá átt að stuðla að vönduðu mati hjúkrunarfræðinga á verkjum og markvissum úrræðum til að draga úr þeim. Þetta er ekki neins konar eftirlit með einstökum hjúkrunarheimilum eða samanburður á þeim, heldur fremur viðleitni til að bæta hjúkrun almennt.

Hér með fer ég þess vinsamlegast á leit við þig að þú verðir þátttakandi í þessari rannsókn. Þátttakan er alveg sjálfviljug og frjáls og þú getur líka hætt hvenær sem er, ef þú vilt. Þarft þú þá ekki að gefa neinar skýringar eða vænta neinna eftirmála, hvorki gagnvart aðstandendum rannsóknarinnar eða öðrum. Hér fyrir neðan eru upplýsingar um rannsóknina og til hvers er ætlast. Ef þú vilt vera með, eftir að hafa lesið þetta blað, þá bið ég þig að skrifa undir samþykkisyfirlýsinguna hér aftast.

Tilgangur rannsóknarinnar er:

að kanna hver er reynsla íbúa á hjúkrunarheimilum af verkjum og óþægindum tengdum þeim. Þannig vonast ég til að fá upplýsingar sem gætu hugsanlega komið að notum í hjúkrun almennt til að meta verki og meðhöndla þá á markvissan hátt, hjá þessum aldurshópi.

Notagildi:

Það er vel þekkt að verkir, bæði líkamlegir og sálræns eðlis, hafa mikil áhrif á almenna líðan fólks. Þegar hins vegar fólk losnar við verkina að einhverju eða öllu leyti, þá hefur það margfeldisáhrif á heilsu og vellíðan til hins betra. Eldra fólk hefur oft verki af fleiri en einum toga. Sumir eru líka veikburða og verða að treysta á hjálp frá öðrum um flest. Íbúar hjúkrunarheimila þurfa yfirleitt að leita til heilbrigðisstarfsmanna um hjálp til að minnka verkina. Mikilvægt er að mat á

verkjum sé þá byggt á þekkingu, úrræðum sé beitt á markvissan hátt og endurmat á árangri sé fyrir hendi.

Rannsóknaraðferð:

Ef þú ákveður að taka þátt í rannsókninni, þá verður ferlið þannig: Ég mun mæla mér mót við þig og taka við þig viðtal, þar sem þú segir mér frá reynslu þinni og upplifun af verkjum og óþægindum tengdum þeim. Það geta verið verkir eða óþægindi sem þú ert að reyna núna þessa dagana, eða fyrr í lífinu, en þó eftir að þú komst á hjúkrunarheimilið. Þetta viðtal tekur ca 1-2 klst.

Ef til vill yrði annað styttra viðtal síðar, þar sem ég spyr nánar um eitthvert atriði.

Viðtölin verða tekin upp á segulband, en algjörum trúnaði og nafnleynd er heitið.

Hvert viðtal fær númer og verða öll rannsóknargögn í öruggri vörslu. Að rannsókn lokinni verður segulbandsspólum og nöfnum eytt. Verði eitthvað skrifað um þessa rannsókn síðar, mun það verða almenns eðlis og hvorki verða hægt að þekkja einstaklinga né hjúkrunarheimili með nafni.

Hugsanleg óþægindi:

Þátttaka í rannsókninni mun ekki að hafa nein óþægindi í för með sér fyrir þig, og kostar þig að sjálfsögðu ekkert peningalega. Þó er hugsanlegt að þér finnist erfitt að rifja upp einhverja óþægilega reynslu. Þú getur þá stöðvað viðtalið og hætt ef þú vilt, eða tekið hlé. Hvort þú tekur þátt eða ekki, breytir engu um stöðu þína hér á hjúkrunarheimilinu. Rannsóknin er gerð með góðfúslegu leyfi yfirstjórnar hér á heimilinu og hjúkrunarfræðingar hafa haft milligöngu um val á íbúum, sem hafa síðan veitt leyfi til að ég komi og útskýri rannsóknina. Eftir það er afskiptum starfsfólks hjúkrunarheimilisins af rannsókninni lokið og starfsfólk hér veit ekki frekar hver er endanlega með og hver ekki.

Kostir við þátttöku:

Þú munt ekki hafa neitt beint gagn af að taka þátt í rannsókninni, peningalega eða á annan veg. Hins vegar kunna þær upplýsingar sem þú veitir að verða framlag til að bæta hjúkrun almennt og verða starfsfólki til hjálpar við umönnun á hjúkrunarheimilum. Mörgum finnst einnig gott að geta talað um reynslu sína við einhvern sem hefur góðan tíma til að hlusta.

Sjálf mun ég ekki hafa peningalegan hagnað af því að gera þessa rannsókn, heldur er hún aðeins liður í námi mínu, eins og áður sagði. Hins vegar hef ég fengið styrk úr rannsóknasjóði til þess að mæta kostnaði og bæta vinutap meðan á vinnu við rannsóknina stendur. Sótt hefur verið um leyfi fyrir rannsókninni til Vísindasiðanefndar eins og lög kveða á um, og hún verið samþykkt.

Spurningar og spjall:

Hafir þú spurningar nú eða síðar þá er þér velkomið að hringja til mín heim eða í GSM síma. Ef til vill vilt þú sýna einhverjum aðstandendum þetta bréf. Ef þeir vilja fá frekari upplýsingar, þá er það velkomið líka.

Rannsakandi:

Guðrún Dóra Guðmannsdóttir, hjúkrunarfræðingur

Bæjargili 50, 210 Garðabær.

S. heima 555-0840, GSM 696-3881

E-mail: gdora@mmedia.is

Translated from the Icelandic

OK

Appendix VIII

Approval

Of participation in the research on pain and pain-related discomfort in the elderly.
Researcher: Guðrún Dóra Guðmannsdóttir, nurse

I agree to participate in the above research project, which entails 1-2 dialogues / interviews, which will be recorded on tape. The dialogues will take place at a spot of your choosing in the nursing home.
The processing of the research data will be as described on the information sheet.

Date

Signature of participant

Translated from the Icelandic
25 November 2001
Terry G. Lacy, Ph.D.
Department of English (ret.)
University of Iceland



Document VII

Samþykkisyfirlýsing

Vegna þátttöku í rannsókn um verki og vanlíðan meðal aldraðra. Rannsakandi:
Guðrún Dóra Guðmannsdóttir, hjúkrunarfræðingur

Ég er samþykk(ur) þátttöku í ofnanefndri rannsókn, sem felur í sér 1-2 viðtöl, sem verða tekin upp á segulband. Viðtölin verða á stað sem þú velur þér á hjúkrunarheimilinu.

Meðferð rannsóknargagna er eins og greint er frá á upplýsingablaði.

Dagsetning

Undirskrift þátttakanda

Appendix VIII

My ideas of participants

- Is on a nursing ward
- Needs to be rather perceptive, i.e., have memory enough to be able to tell of his or her experience and express himself or herself in comfortable and unhurried situations. (Note: the stress is not on facts so even though people do not remember precisely, for example, timing, places and such they could possibly participate.
- Has some pain, using person's own estimation of what is pain.
- This can be either constant or intermittent pain. (Do not include people whose pain is so well managed that it does not interfere with their activities of daily living).
- There is persistent pain, i.e., it has been evident for at least three months and while the person has been in a nursing home.
- Can be an experience of pain that is no longer there, but was evident while the person was in a nursing ward and he or she remembers well enough.
- What kind of pain? For example, pain because of arthritis, arthrosis, osteoporosis, low back pain, pain as a result of hemiplegia, because of Parkinson's disease, headache, or pain following herpes zoster. Could even be pain due to cancer. Not acute pain like angina pectoris, pain because of duodenal ulcer, etc.

For more information:
Guðrún Dóra Guðmannsdóttir
Tel. 555-0840

Document VIII

Hugmyndir mínar um viðmælendur

- Er á almenntri **hjúkrunardeild**
- Þarf að vera **nokkuð greinagóð/ur**, þ.e. hafa nokkuð gott minni á reynslu sína og geta tjáð sig við rólegar og þægilegar aðstæður. Athugið: áherslan er ekki á staðreyndir, þannig að þó fólk muni ekki nákvæmlega td. tímasetningar, staði og slíkt þarf það ekki að koma að sök.
- Hefur verki. **Mat viðkomandi sjálfs á hvað eru verkir gildir hér.**
- Það geta **hvort heldur verið stöðugir verkir eða verkir sem koma við og við**. (Ekki þó fólk sem er það vel verkjastillt að verkirnir hafa ekki teljandi áhrif á líf þeirra og líðan..)
- Um er að ræða **langvinna verki**, (þ.e. hafa staðið í 3 mánuði eða lengur) meðan viðkomandi dvaldist á hjúkrunardeild.
- **Má vera verkjareynsla sem er liðin**, en hafi þó staðið meðan viðkomandi var á hjúkruanardeild, og hann/hún man vel eftir.

Hvernig verkir? Dæmi: vegna liðagigtar, slitgigtar, samfalls á hrygg; bakverkir, verkir sem afleiðing af lömun, verkir vegna Parkinson sjúkdóms, höfuðverkir, eða verkir eftir ristil (Herpes Zoster). Gætu jafnvel verið verkir vegna krabbameins. Ekki bráðir verkir eins og hjartverkur, v/magasárs ofl. slíkt.

Appendix IX
To ward sisters
concerning the study on pain and discomfort in elderly people

Name of participant: _____

State ID no. _____

Came to the ward : day. _____ month _____ year _____

Does the participant use analgesics on a permanent basis: Yes ____ No ____

Does the participant receive medicine apart from the PRN: Yes ____ No ____

Is there some other treatment being used to relieve the participant of pain, i.e., hot pads, massage etc. Yes ____ No ____

How much influence on the participant's activities of daily living do you think this pain and discomfort has:

no _____ little _____ moderate _____ much _____ very much _____

For further information:
Guðrún Dóra Guðmannsdóttir
Tel. 555-0840

Document IX

Til deildarstjóra

varðandi rannsóknina um verki og verkjamat hjá öldruðum

Nafn: _____

Kennitala: _____ - _____

Kom til vistunar á hjúkrunarheimilið : dagur: _____ mán. _____ ár _____

Er viðkomandi á föstum verkjalyfjum: Já _____ Nei _____

Fær viðkomandi verkjalyf þar fyrir utan (PN): Já _____ Nei _____

Er önnur meðferð í gangi til að draga úr verkjum s.s. bakstrar, nudd, ofl. ?

Hve mikil áhrif á daglegt líf og virkni viðkomandi hafa verkir þessir og vanlíðan tengd þeim (að þínu mati):

engin _____ lítil _____ nokkur _____ mikil _____ mjög mikil _____

Frekari upplýsingar:

Guðrún Dóra Guðmannsdóttir

s. 555-0840

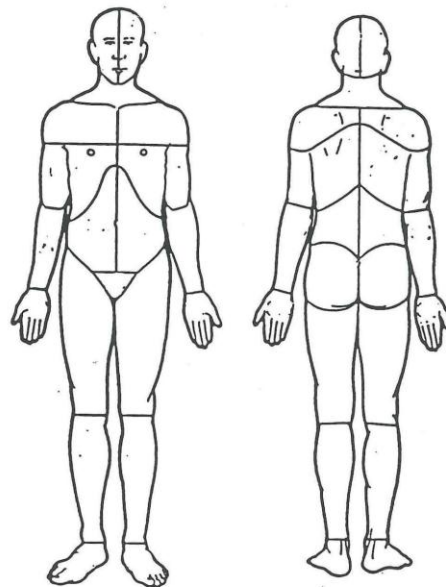
Appendix X

Pain-mapping for the elderly

1. Intensity of pain

*	*	*	*	*	*
No pain	Mild pain	Moderate pain	Severe pain	Very severe pain	Worst possible pain

2. Site of pain



3. Frequency of pain

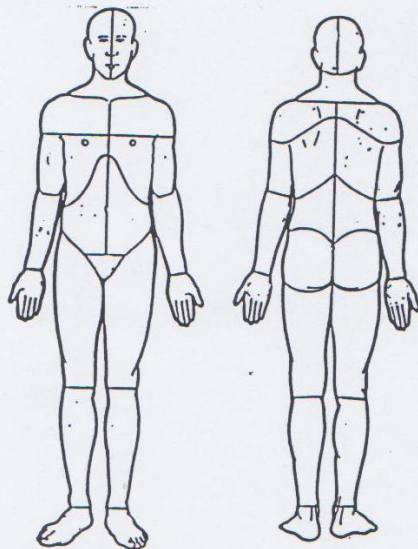
4. Description of pain (stinging, throbbing, etc.)

Picture reprinted from Margolis et al. (1996)
GDG, 2001

VIÐTAL UM VERKI

STYRKLEIKI VERKJARINS:

STAÐSETNING:



HVE OFT OG HVENÆR SÓLARHRINGS:

LÝSING Á VERK (t.d. stingandi, krampakenndur osfrv)

GDG 2001