Living with Long-Term Pain after a Stroke

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We've heard that nowadays there's no need for anybody to be in pain ...
... but what's this then?

Two of the participants
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ABSTRACT

The general aim of this thesis was to classify and describe long-term pain two years after a stroke and to describe the experiences of pain, and the consequences it has on the persons’ lives. The studies were conducted from a multidimensional perspective on pain, combining quantitative and qualitative methods. Three types of long-term pain were classified and described among the 43 participants included, aged 33–82 years. These were central post-stroke pain, nociceptive, mainly shoulder pain, and tension-type headache. Pain onset, within one to six months in most of the cases was after discharge from the hospital. Continuous pain or pain almost every day was reported by nearly two-thirds. The pain was mostly described as troublesome, annoying and tiring in all pain groups. The rating of pain intensity revealed individual differences among the participants within the pain groups. In addition to long-term pain, the participants suffered several impairments and nearly half of them were dependent on others, and two-thirds on assistive devices. Several coping strategies were described, most often problem-focused. Their health-related quality of life was decreased, mostly related to their long-term pain and physical impairments. Their experiences of caring revealed the need of improvements in knowledge about long-term pain, attention and understanding among the professionals, and continuity in the contacts.

Keywords: stroke, central pain, chronic pain, neuropathic pain, nociceptive pain, shoulder pain, tension-type headache, pain assessment, disability, activities of daily living, coping, health-related quality of life, mood, caring.

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ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


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V. Widar, M., Ek, A-C. & Ahlström, G. Caring and uncaring experiences as narrated by persons with long-term pain after a stroke; (Submitted for publication).

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ABBREVIATIONS

IASP  International Association for the Study of Pain
MONICA  World Health Organization (WHO) Multinational Monitoring of Trends and Determinants in Cardiovascular Disease (MONICA) project

DEFINITIONS

Allodynia  Pain due to stimulus which does not normally provoke pain. A change in the quality of sensation; tactile, thermal or other, normally not painful but the response is painful*
Central sensitization  An increase in the excitability and responsiveness of neurons in the spinal cord
Hyperalgesia  An increased response to stimulus which normally is painful. A consequence of perturbation of the nociceptive system with peripheral or central sensitization*
Hypoalgesia  Diminished pain in response to a normally painful stimulation*
Pain threshold  The least experience of pain which a subject can recognize.*

* (IASP, 1994).
CONTENTS

INTRODUCTION 1
BACKGROUND 2
Stroke 2
Pain 3
 Definitions of chronic or long-term pain 4
 Long-term pain after stroke 5
 Pain assessment 7
Disability 9
Coping 10
Health-related quality of life 12
Caring 13

AIMS 16

METHODS 17
Design 17
Selection of participants 20
Data collection 22

Quantitative investigations 22
 Pain assessment 23
 Disability 26
 Health-related quality of life 27
 Statistical methods 28

Qualitative investigations 29
 Pain experience 29
Coping 29
Health-related quality of life 29
Caring 30
Qualitative analysis 30
INTRODUCTION

A stroke incident leaves one in a situation involving new and stressful thoughts and emotions concerning one’s present and future life. The consequences may be several obvious and/or invisible impairments that influence one’s functioning and whole life situation. Many who have suffered a stroke remain dependent on others and are in need of health care. The weakest part in the care of persons who have suffered a stroke, though, is after the discharge from the hospital to other forms of care or to their home (National Board of Health and Welfare, 2002). There is a need of professional competence and a well-functioning team-work a long time after the stroke incident, as has recently been emphasized by the National Board of Health and Welfare (2002).

The risk of suffering a stroke increases with age. It is common knowledge that stroke is disabling, and the most commonly known impairments are related to motor and cognitive functioning, speech and mood. In research and practice, much attention has been given to the life-threatening consequences and the impairments causing problems in daily care and in communication (National Board of Health and Welfare, 2002).

Little attention has been given to pain following a stroke as compared with the other consequences, and pain has been reported to be a neglected and difficult area within health care, especially in community health (Bowsher, 2001; Blomqvist & Edberg, 2002; Tuner-Strokes & Jackson, 2002). Pain after a stroke may occur at onset but most often several months or years later, still related to the stroke (Vestergaard, et al., 1993; Bowsher, 1996; Snels, et al., 2002). None of the previous studies on pain related to stroke have described the persons’ disability and functioning, how the pain is experienced and how it influences their everyday life and quality of life. Nor has there been consideration of how the persons cope with their pain or what they think about how they have been cared for with regard to their pain. The need of a broader perspective than has been applied in previous studies, which takes account of the sufferers’ perspective is obvious, since long-term pain is reported as influencing all aspects of life.
BACKGROUND

Stroke
The World Health Organization (WHO) has stated stroke to be clinically defined as an acute neurological dysfunction of vascular origin with sudden or at least rapid occurrence of symptoms with signs corresponding to the focal areas of the brain. The loss of function can at times be global. Symptoms last more than 24 hours or the stroke incident leads to death (World Health Organization, 1989). This excludes a transient ischemic attack (TIA) or cerebrovascular lesion (CVL) events in cases of blood disease or brain tumours, and secondary CVL caused by trauma (Truelsen et al., 2003). There are three main types of stroke: brain infarction, which causes 85% of all lesions in Sweden; intracerebral haemorrhage, 10%; and subarachnoidal haemorrhage, 5% (Riks-Stroke, 2002).

The incidence and mortality rates of stroke have shown great variation between different parts of the world and between countries on the same continent (Warlow, 1998; Weir et al., 2001; Truelsen et al., 2003). In Sweden, approximately 25-30 000 persons suffer a stroke each year. Of these, 20 000 are first-ever strokes. During the years 1999-2000, 49% of those who suffered a stroke were women and 51% were men (Riks-Stroke, 2002). Appelros et al. (2002) reported a higher incidence of first-ever stroke among women than men in all age-groups, whilst a study by Pessah-Rasmussen et al. (2003) reported an increase in the middle-age population of men. Approximately 80% are 65 years or older at the time of the stroke incident with a mean age of 75 years (men 73 years and women 77 years), (Riks-Stroke 2002). Up to 40% are reported to die within a year of onset (Glader et al., 2001; Appelros et al., 2002).

The total prevalence of stroke is estimated to be 100 000 in Sweden, and 20 000 of the persons affected are in need of access to care day and/or night (National Board of Health and Welfare, 2002). The prevalence is likely to increase over the next few decades, because of an increasing elderly population and because the long-term survival after stroke is improving (National Board of Health and Welfare, 2002; Terént, 2003). The long-term survival may reflect improvements due to better
diagnostics, stroke care and prevention (Asplund et al., 2003; Terént, 2003). It is estimated that the increasing number of elderly people in the population will lead to 30% more stroke incidents by 2010 if the incidence remains unchanged (National Board of Health and Welfare, 2002). This means that the need of care of stroke patients is likely to increase unless there are further improvements in the prevention and management of stroke (Terént, 2003; Sundberg, Bagust & Terént, 2003).

Stroke is a heterogeneous disease involving a risk of developing a number of medical disorders that may occur a long time after the stroke incident. Among these has pain been mentioned (Nydevik et al., 1993; Davenport et al., 1996; Glader et al., 2001). The National Board of Health and Welfare (2002) now state that investigations of the aetiology of the pain and prevention of pain in stroke patients have to be performed.

**Pain**

Pain has been a concern for mankind since our beginnings, and varied efforts have been made to understand it (Rey, 1998; Vertosick, 2000; Bonica & Loeser, 2001). The emotional and physical consequences of long-term pain have been described by scientists, writers and poets, and the meaning of pain has been a question through history (Johannisson, 1997; Bonica & Loeser, 2001). The punishment aspect is common and is related to its incomprehensibility and inability to give pain a sense of coherence. Pain has in all cultures been a source of imagination, mysticism or superstition (Johannisson, 1997; Vertosick, 2000). The term pain is often used to express a psychological suffering, and the concept of suffering is closely related to long-term pain (Breen, 2002).

During the 19th and 20th centuries there was an improvement in the understanding of pain and pain mechanisms, and pain theories were formed. One of them, the Gate control theory, provided a conceptual framework for integrating not only the sensory but also the affective and cognitive dimensions of pain (Bonica & Loeser, 2001). The pain speciality, algology (Greek *algos*), was also established around the middles of the 20th century (Rey, 1998; Vertosick, 2000; Bonica & Loeser, 2001).
The challenge today is to increase the understanding of brain function, since pain and the cognition of pain is complex and influences brain processing on many levels (Ingvar & Hsieh, 1999; Melzack, 1999; Carr, 2002). A more complex approach to pain physiology than has previously been used, takes into account the plasticity of all of the pathways of pain and its central sensitization (Melzack, 1999; Wall, 1999). Further development of pain theories to explain the basis of chronic pain is under investigation (Melzack, 1999; Bonica & Loeser, 2001). In the field of neuroradiology, new techniques have been introduced such as functional magnetic resonance imaging (FMRI) that hopefully will improve our understanding of the underlying mechanisms (Ingvar & Hsieh, 1999).

Definitions of chronic or long-term pain

Pain is one of the most commonly reported symptoms and because of its subjective nature it is expressed in various ways by individuals and within cultures (Peolson, Hydén & Sätterlund Larsson, 2000; Vertosick, 2000; Bonica & Loeser, 2001). A distinction between acute and chronic pain was made only a few decades ago (Merskey & Bogduk, 1994; Bonica & Loeser, 2001). Another distinction within chronic pain has also been made using the term chronic non-malignant pain for pain not relating to cancer, and chronic widespread pain (CWP) for generalized pain syndromes (Loeser, 2001; Turk & Okifuji, 2001). Chronic pain has been recognized as pain that has persisted beyond the normal tissue healing time, in non-malignant pain usually considered as three months (Merskey & Bogduk, 1994). Another criterion for chronic non-malignant pain is pain that extends beyond the expected period of healing, which is relatively independent of time (Turk & Okifuji, 2001). For research purposes, six months’ duration of pain has been suggested (Melzack & Bogduk, 1994), but standard international definitions of chronic pain are not available. In Sweden, the term chronic is used to denote pain existing for at least six months, which does not imply that the pain is incurable and/or continuous. The term long-term pain would appear more accurate, since chronic is generally described as designating a persistent, incurable condition (National Board of Health and Welfare, 1994). The term long-term
has been used in this thesis instead of the term chronic because chronic may imply unnecessarily pessimistic attitudes and expectations.

Melzack & Wall (1996) state that pain research has not yet advanced to the stage at which an accurate definition of pain can be formulated. They suggest that there should be guidelines for a definition rather than a definition in itself until we have adequate knowledge about pain mechanisms. The definition often cited is the one included in the IASP Pain Terminology: “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain, 1994, p. 2). Pain may also occur in the absence of identified tissue damage. IASP (1994) clarifies this definition by stating that pain is always a subjective experience and is determined by the specific context and the meaning persons give to their pain. McCaffery made an additional clarification in 1968, for use in clinical practice; “pain is whatever the experiencing person says it is, and existing whenever the experiencing person says it does” (McCaffery & Pasero, 1999, p. 17).

Today most pain scientists emphasize that pain is multidimensional, including sensory, emotional, cognitive and behavioural dimensions (Melzack & Wall, 1996; Bonica & Loeser, 2001). This way of describing pain diminishes the risk of regarding pain as either physical or psychological. Psychologists have introduced a classification; affective, evaluative and motivational, to identify specific psychological components, and they also consider the psychosocial dimension (Turk & Okifuji, 2001).

**Long-term pain after stroke**

The two most commonly described types of pain after a stroke are central post-stroke pain (CPSP) and shoulder pain (Bowsher, 1995; Segatore, 1995; Jespersen et al., 1995). Tension-type headache has also been reported (Vestergaard et al., 1993). Since all participants included in this thesis have suffered a stroke, the CPSP is named central pain.

Central pain in stroke was first described as the thalamic pain syndrome, by Dejerine & Rossy in 1906, but gradually evidence has shown that central pain may
occur after a CVL in other locations of the brain than the thalamus (Leijon et al., 1989). Central pain is a neuropathic pain syndrome predominantly originating anywhere in the spinothalamocortical pathway in the brain with sensory deficit, commonly described as burning pain (Boivie, Leijon & Johansson, 1989; Andersen et al., 1995; Bowsher, Leijon & Thoumas, 1998; Weimar et al., 2002a). Central pain after a stroke has been reported in 8-11% (Leijon, Boivie & Johansson, 1989; Andersen et al., 1995; Bowsher, 2001; Weimar et al., 2002a) and in 25% in a study on Wallenberg’s syndrome, i.e. lateral medulla infarction (MacGowan et al., 1997). The pain onset may be immediate but most often it is some months later. Up to 3 years (Leijon, Boivie & Johansson, 1989), and even up to 6 years, has been reported (Bowsher, 1996). Abnormality of thermal perception of pain in the body parts with sensory deficits is characteristic in central pain, but may not always be evident (Bowsher, Leijon & Thoumas, 1998; Boivie, 1999; Vestergaard et al., 2001; Ahmad & Goucke, 2002).

It has been reported that the occurrence of shoulder pain during the 1980s was up to 84% and that during the 1990s it was between 22-64% (Snels et al., 2002; Turner-Stokes & Jackson, 2002). The onset may vary from the stroke incident up to 18 months later but seems to increase with time (Snels et al., 2002; Ratnasabapathy et al., 2003). Pain in the shoulder may be related to brain lesion or only to the joint, or both, which means that either nociceptive and/or central pain may be present. Shoulder pain is often related to severity of paralysis in the upper limb but also to soft tissue damage, spasticity or subluxation. Most often several factors are involved due to the complex functional and structural anatomy of the shoulder. It is one of the most frequent complications of hemiplegia. Poor handling and positioning of the affected upper limb has been reported to contribute to shoulder pain (Walsh, 2001; Gamble et al., 2000; Gardner et al., 2002; Vaught & Chantraire, 2003). Shoulder pain is reported to interfere with function and quality of life, and to complicate the rehabilitation process (Snels et al., 2002; Turner-Stokes & Jackson, 2002).

Tension-type headache is a multifactor disorder with an increased pericranial muscle tension, and in the chronic form often with the contribution of psychological variables such as stress (Vestergaard et al., 1993; Ferro, Melo & Guerreiro, 1998).
Only a few studies have reported tension-type headache, which is the most common type of headache after a stroke incident, usually described as pressing or throbbing (Vestergaard et al., 1993; Ferro, Melo & Guerreiro, 1998). Late onset headache may occur up to years after the stroke incident, still related to the CVL (Mitsias & Ramadan, 1992). There is no consensus about the incidence of long-term tension-type headache after stroke, even though it is reported to be common. Nor is there any consensus about gender differences, whether in relation to infarction or haemorrhage or to the location or size of the brain injury (Vestergaard et al., 1993; Ferro, Melo & Guerreiro, 1998).

**Pain assessment**
The assessment of long-term pain should be based upon a multidimensional perspective of pain and performed in a relaxed atmosphere (McCaffery & Pasero, 1999; Melzack & Katz, 1999; Turk & Okifuji, 2001; Clark et al., 2002). This includes aspects of a person’s experiences with regard to how pain is related to physical, emotional and social functioning, as well as cognitive and behavioural aspects (Turk & Okifuji, 2001). In order to get a comprehensive view, a pain assessment should therefore comprise how the pain is experienced, a pain analysis and a physical examination.

There are today no entirely objective measures for pain, so it is important to rely on the person’s self-reports and adopt the person’s perspective. The attitude of the investigator is of importance since this may influence the pain assessment (McCaffery & Ferrell, 1997; Jensen & Baron, 2003; Turk & Okifuji, 2003). The anamnesis, in the form of a dialogue with the person is a sovereign base, and a good interview provides a wide range of information (Hamilton, 2000; Peolsson, Säljö & Sätterlund Larsson, 2000; Turk & Okifuji, 2003). This should include such factors as the problem and concerns from the person’s own perspective, how the person expresses the pain and what he/she has done to attempt to alleviate the pain. Further, the person’s experiences and expectations with regard to health care should be included (Turk & Okifuji, 2003). The language used is of importance, since most people use everyday language to describe their pain, most often without using the word pain (Schmidt Luggen, 1998;
Kamel et al., 2001). In the Swedish language the words pain, hurt and ache might be used interchangeably in ordinary conversation (Peolsson, Säljö & Sätterlund Larsson, 2000).

The questionnaires used for pain analysis in clinical practice are most often used to determine the pain location, intensity, quality, frequency and duration. Further, they are used to assist choice of therapy and to evaluate the effectiveness of different therapies (Melzack & Katz, 1999). The parameters included in these questionnaires concern mainly the sensory aspects, which is one form of structured data collection concerning the physical aspects of pain. Some pain questionnaires also include what exacerbates or increases the pain and what alleviates or decreases it (McCaffery & Pasero, 1999; Turk & Okifuji, 2003).

Pain intensity, whether acute or long-term, is the most frequent measure of pain. There are different kinds of scales for measuring the intensity, such as visual, numerical, verbal, and face rating scales, and these may be horizontal or vertical (Melzack & Katz, 1999; McCaffery & Pasero, 1999; Paul-Dauphin, 1999; Campbell, 2003). It has been emphasized that the person requires a thorough explanation of the measure from a trained investigator, and it is recommended that patients should do the measuring themselves (Huskisson, 1974; McCaffery & Ferrell, 1997). Long-term pain is complex to measure, and since pain may vary during the day and between days, a single measure of current pain is inadequate. If the intention is to measure the average pain, the validity will be improved by increasing the number of measures several times a day for a period of time (Jensen & McFarland, 1993; Campbell, 2003; Turk & Okifuji, 2003).

The quality of pain is another common pain measure making use of pain word descriptors for the sensory and affective dimensions (Melzack, 1987; Burckhardt & Bjelle, 1994; Melzack & Katz, 1999; Campbell, 2003), which are most often included in pain questionnaires and may be quantified.

In the assessment of long-term pain, a physical examination is important, especially when the type of pain is unknown (Jensen & Gottrup, 2003). In the assessment of pain after a stroke it is especially important to distinguish central from nociceptiv pain. One way to classify, in addition to a thorough neurological
examination of sensory signs, is by thermal quantitative analysis of sensory abnormalities (Boivie, Leijon & Johansson, 1989; Gracely, Eliav & Hansson, 2003). The diagnosis of central pain requires exclusion of other causes of pain in order to provide adequate treatment (Bowsher et al., 2001; Vestergaard et al., 2001).

The person’s life situation, including pain and dimensions relating to pain such as coping and quality of life is of importance in the overall assessment. This is especially important in the case of persons with long-term pain and disability, in attempts to find ways of relieving pain.

Disability
The consequences of stroke are complex and can be studied from different perspectives. The WHO has recently proposed a new International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) which serves as a conceptual framework. In this version the term handicap has been excluded. ICF classifies health and health-related states, and does not classify the people, but describes the situation of each person within the context of environmental and personal factors. ICF has two parts, each with two components: 1. Functioning and disability, including the components body function and structures, and activity and participation; 2. Contextual factors, including the components environmental factor and personal factors. The components of functioning and disability can be used to indicate problems, e.g. impairment, activity limitation or participation restriction, summarized under the umbrella term disability. The definitions included in ICF are the following: impairment is a problem in body function or structure such as significant deviation or loss; activity limitation refers to difficulties an individual may have in executing activities, tasks or actions; participation restriction has to do with problems an individual may experience when it comes to involvement in everyday situations (World Health Organization, 2001). The distinction between disability and functioning is not easy, since there is no “gold standard” (Dahl, 2002).

Stroke is today the major cause of long-term disability in adults and is the most common reason that people older than 60 years require rehabilitation. At least half of all those who suffer a stroke remain partly or fully dependent on others for their
activities of daily living (ADL) (Löfgren et al., 1998; Glader et al., 2001; Rothwell, 2003). A stroke incident has therefore potentially physical, emotional and socioeconomic impact on the person, the family and the health services (Terént, 2003). Women seem to suffer more impairments and dependency than men after a stroke (Wyller et al., 1997; Glader et al., 2003) but men have been reported to receive more day-rehabilitation than women in recent years in Sweden (Riks-Stroke 2002).

The lack of or decreased ability to perform daily activities has become an indicator of disability (Sonn, 1996). In daily activities, a distinction can be made between personal activities of daily living (P-ADL) and instrumental activities (I-ADL) (Sonn & Hulter Åsberg, 1991). P-ADL comprises basic daily human activities that have to be accomplished by all people. I-ADL is more complex and comprises activities that are essential for living an independent life in society (Törnquist, 1995; Avlund, 1997).

Long-term pain has been reported to be associated with physical disability in the elderly but in other cases it seems to have minimal physical impact (Farrell, Gibson & Helme, 1996). Long-term pain may, however, impair the person’s function, socially, vocationally and psychologically (Craig, 1999). If disability be defined as the inability to carry out certain activities because of a medical problem, then long-term pain may be seen as associated with disability (Robinson, 2003).

Coping
Stress is a natural part of life, and the managing of stress is of decisive importance for the person’s well-being. Conceptualization of stress and coping is derived from various fields. Early work on stress by Cannon 1932 (Lazarus & Folkman, 1994) focused on physiological reaction to stressful stimuli. In 1936 Selye who has been seen as the father of the modern stress research, continued Cannon’s previous studies with clinical observations and laboratory research (Lazarus & Folkman, 1984). There are two approaches to coping within the cognitive-behavioural perspective: one emphasizes the style, treating coping as a personality characteristic, which is inner psychodynamics, and the other emphasizes coping as a process including environmental influences (Lazarus, 1993). The latter involves considering stress as a
transactional phenomenon dependent on the meaning of the situation to the perceiver. This is a phenomenological theory whereby one views stress as a relationship between a person and the environment (Lazarus & Folkman, 1984; Lazarus, 1993). The person evaluates the potential threat, loss or challenge on the basis of what it means to his or her well-being, which is the primary appraisal. What is appraised as stressful is individual and depends both on the current situation and on personal values and previous experience.

Lazarus & Folkman defines coping as: “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resource of the person” (Lazarus & Folkman, 1994, p. 141). When the person experiences stress, secondary appraisal occurs, this means that the person considers his or her ability to manage it. The primary and secondary appraisals are integrated and should not be seen as existing in a cause and effect relation. Coping requires cognitive and behavioural efforts, which excludes automatized behaviours and thoughts (Lazarus & Folkman, 1984; Lazarus 1993). Coping efforts are independent of outcome, and the term coping is used whether the process is successful or not (Lazarus, 1993). Coping efforts are referred to as either problem-focused, when they are directed towards changing the cause of the stress, or as emotion-focused when they are directed towards changing the way one thinks or feels about a stressful situation. In daily life, both problem- and emotion-focused coping may be used in the same situation (Lazarus & Folkman 1984).

Persons who have suffered a stroke may have to cope with various kind of stress because of the different changes in their life situation (Sisson, 1998; Nilsson, Jansson & Norberg, 1999; Burton, 2000). Long-term pain may imply additional stress in the form of fear, anger, anxiety and depression (Keefe, Salley & Lefebvre, 1992). It is often difficult to determine which one is the primary stress in pain and which one is secondary since different sources of stress interact (Keefe, Salley & Lefebvre, 1992; Katz et al., 1996). Substantial individual differences have been reported to exist in the coping strategies people use to modulate their pain. Attentional diversion, cognitive reconstructuring and self-relaxation may serve as coping strategies for some, but distraction alone appears to offer insufficient pain relief (Craig, 1999). Therefore there
is a need of knowledge about coping strategies for individuals in the case of given
types of stress, at given times and under given conditions (Lazarus & Folkman, 1984;
Lazarus, 1993; Katz et al., 1996). The pain literature reveals instruments for assessing
coping with long-term pain. One approach has been to assess coping using
questionnaires that ask the person to specify and say how they respond to the primary
stress in their life, whether it is pain or not. Another approach has been to develop
stress-specific coping questionnaires that ask the person to report the manner in which
they cope with long-term pain. The choice of approach depends, however, on the
purpose of the assessment (Katz et al., 1996).

Lazarus (1993) says that there has been little research about coping strategies
across different kinds of stressful encounters with an inductive approach. One attempt
at solving the problem with the interaction of multiple stress experiences is to ask the
persons themselves, this in order to ascertain which type of stress they are coping with
and how they are managing it.

Health-related quality of life
During the past thirty years, quality of life (QoL) and health-related quality of life
(HRQoL) have been investigated. HRQoL has been used as an indicator of medical
and caring interventions. There have been different definitions of the concept QoL,
and consequently QoL has been measured in different ways (Anderson & Burckhardt,
1999; Smith, Avis & Assmann, 1999). QoL can be taken as designating either generic
quality of life or health-related quality of life. The distinction between these has not
always been considered.

The concept HRQoL mainly refers to disease-related functioning and well-being
(Sullivan, Karlsson & Ware, 1994; de Haan et al., 1995), or to medical factors and
conceptualizations of HRQoL include the dimensions of physical, social and role
functioning, mental health, and general health. Concepts such as vitality, pain and
cognitive functioning are subsumed under these. Biological and physiological
variables are only occasionally included in the conceptualization of HRQoL, say
In Scandinavia, Nordenfelt (1995) sees the concept QoL as happiness with one’s life, emerging from well-being and the achievement of personal goals, which covers all positive human experiences (1994). Naess (2001) refers to QoL as psychological well-being and says that QoL is high when a person’s cognitive and affective experiences are positive and low when their experiences are negative.

Internationally, it is today commonly agreed that QoL is multidimensional. The WHO quality of life group (WHOQOL), has suggested the definition as: “individuals’ perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1998, p. 551). This definition refers to a subjective evaluation, embedded in cultural, social and environmental context and is seen as a broad concept comprising the entire life, also including health.

It is well-known that many stroke survivors have a deteriorated health-related quality of life due to decreased functioning in several respects (de Haan et al., 1995; Carod-Artal et al., 2000). Apart from stroke, pain is reported to have a great impact on a person’s quality of life (Ferrell, 1995; King, 1996; Gerstle, All & Vallace, 2001). Long-term pain imposes stress on the person and causes considerable suffering in everyday life that affects quality of life, but the responses to the suffering vary among the persons afflicted (Craig, 1999). No study has previously been published on HRQoL concerning only persons with long-term pain after a stroke. Therefore it is of importance to ask the persons afflicted to describe their experiences.

Caring

Care is a basic human need, provided in various ways and by different people. Self-care is fundamental and refers to personal care that individuals require for functioning and development (Orem, 1995). Dependent care is provided by non-professionals such as next of kin or professionals when a person is unable to regulate their health-related functioning and/or development. The professional requires, in addition to skill and knowledge, specific competencies and compassion (Morse et al., 1991; Orem, 1995; Halldórsdóttir, 1996).
Heidegger (1981) describes the relationships between human beings that may be applied to caring as being for, against, or without one another. Being without one another mean passing one another without paying attention or without showing concern for one another. Riemen (1986) introduced the question of god or bad caring within nursing on the basis of clinical experiences. This was because nursing and caring had mainly been presented in a positive way connected with competence and good relations (Riemen, 1986). Further studies about caring or noncaring, caring or uncaring, and god or bad caring have been reported (Kyle, 1995; Halldórsdóttir, 1996; Lövgren, Engström & Norberg, 1996), but Gaut (1986) stated that such distinctions are a matter of degree in caring. Gaut (1983, 1986) presented the terms caring for and caring about. Caring for requires a capacity to understand others’ experiences, their needs and goals. Caring about has to do with in what manner the care is performed, which may be a visible quality marker for caring interventions. Caring is in this sense an action and/or an attitude, i.e. a task and/or relation. Caring for can be done with or without caring about (Gaut, 1983; 1986; Jecker & Self, 1991; Norberg et al., 1992; Åström, 1995). Caring may be described from either the patient’s or the professional’s perspective. Though the latter perspective is obviously important, it is the patient’s perspective that is the crucial one.

Riks-Stroke (2002) report that among the persons living at home before the stroke, 60% were able to return home without home-help service, though they often received help from their next of kin in their daily life. Sixteen per cent needed institutional care. In a study performed two years after a stroke, like this thesis, 52% often or always reported tiredness, 24% depression, 19% anxiety and 27% pain and cognitive impairments involving reading, writing or speech were reported by 38-59% (Glader et al., 2001).

Pain has been reported to be a great problem for the individual in both care and rehabilitation (Nydevik et al., 1993; Bowsher, 1995; Davenport et al., 1996; Turner-Stokes & Jackson, 2002). In spite of this, pain conditions after stroke have only recently been included as a consequence of stroke in national reports in Sweden (National Board of Health and Welfare, 1999, 2002). In previous studies on pain after stroke, the focus has been on the pathophysiology of only one type of pain condition in
each study, even though three types have been reported (Vestergaard et al., 1993; Andersen et al., 1995; Jespersen et al., 1995). Therefore it is of interest to study long-term pain after a stroke two years after the stroke incident with a broader perspective.
AIMS

The general aim of this thesis was to classify and describe long-term pain two years after a stroke and to describe the experiences of pain, and the consequences it has on the persons’ lives.

The specific aims for the studies included were:

- to classify and describe the characteristics of different long-term pain conditions after a stroke (I)

- to describe disability after a stroke and how long-term pain influences everyday life according to the Multidimensional Pain Inventory-Swedish language version (MPI-S) and to test the reliability of this instrument (II)

- to describe pain, coping strategies, and experienced outcome of coping with the three previously classified long-term pain conditions after a stroke (III)

- to describe health-related quality of life in persons with long-term pain after a stroke, and to compare this with different types of pain conditions, age, gender and household status (IV)

- to describe how persons with long-term pain after a stroke experience their care (V).
METHODS

Design
The studies included in this thesis were conducted from a multidimensional perspective on pain and the consequences of living with pain. The research design, combining quantitative and qualitative methods, is descriptive and includes comparative and correlational analysis. The design and methods were chosen to be complementary in respect of gaining knowledge and understanding of long-term pain conditions after a stroke (Morgan, 1998; Brink & Wood, 1998). The design and methods are presented in Table 1.

The studies included in this thesis with a deductive approach, following the nomothetic tradition of science, were mainly performed in order to get data it would be possible to compare. Further to gain knowledge about differences with regard to pain, disability and health-related quality of life. Also to test the reliability of an instrument previously developed for chronic pain patients (I, II, IV). The ontology or view of reality is atomistic within the nomothetic tradition and focus on what is general. A phenomenon can be studied objectively and independently out of context, using measurements and discovering interrelationships through quantitative data and statistical analysis (Barbosa da Silva & Andersson, 1993; Nilstun, 1996; Hartman, 1998).

The studies with an inductive approach were performed in order to gain a deeper understanding and greater knowledge of the participants’ experiences of pain, coping, health-related quality of life and care (III, IV, V). The ideographic tradition of science implies focusing on the understanding of concrete, individual and unique experiences, and their underlying meaning. The studies performed are interactive and have a naturalistic interpretative approach. The ontology or view of reality is understood in its context and is presumed to be holistic, which means that the context is necessary for the understanding of the phenomenon. The significance of experience is studied by collecting data, often narrative data, and by using qualitative methods of analysis (Lincoln & Guba, 1985; Denzin & Lincoln, 1994; Nilstun, 1996; Patton, 2002).
Table 1. Design and methods used in the studies of persons with long-term pain after a stroke (n=43)

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Data collection</th>
<th>Methods of analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Descriptive</td>
<td>Pain assessments: Clinical examinations - Medical examination - Thermal quantitative sensory testing (QST)</td>
<td>Statistical analysis: - descriptive - comparative</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Questionnaires: - Pain-O-Meter - Pain questionnaire</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>Descriptive</td>
<td>Questionnaires: - ADL staircase - Assistive devices - Self-report impairment - Multidimensional Pain Inventory - Swedish language version (MPI-S)</td>
<td>Statistical analysis - descriptive - comparative - correlational</td>
</tr>
<tr>
<td>III</td>
<td>Descriptive</td>
<td>Qualitative interview about - Pain and pain experiences - Coping</td>
<td>Latent and manifest content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Descriptive</td>
<td>Qualitative interview about - Health-related quality of life</td>
<td>Latent content analysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Questionnaires: - SF-36* - HAD Scale**</td>
<td>Statistical analysis: - descriptive - comparative</td>
</tr>
<tr>
<td>V</td>
<td>Descriptive</td>
<td>Qualitative interview about - Experienced caring</td>
<td>Latent content analysis</td>
</tr>
</tbody>
</table>

*n=40 **n=41
Scientific theorists, most notable Aristotle (384-322 B.C.) and later Dilthey (1833-1911), have established the dichotomy of science, i.e. one branch for causal explanation and one for hermeneutical understanding. These have been seen to be opposites, but although their aims and methods differ, both are seeking justification for the knowledge obtained (Barbosa da Silva & Andersson, 1993; Hartman, 1998, Føllesdal, Valløe & Elster., 2001). There is a growing recognition that the distinction has created an unnecessary divide (Pope & Mays, 1995; Morgan, 1998). The hypothetic-deductive method, testing and verifying hypotheses, has within the nomothetic tradition been seen as the most highly developed scientific method, and among proponents of hermeneutics the hermeneutical understanding has been emphasized (Barbosa da Silva & Andersson, 1993; Føllesdal, Valløe & Elster., 2001). The hypothetic-deductive method is seen by Føllesdal, Valløe & Elster (2001) as a very general approach and in deed as forming the basis for most sciences, but this does not imply it is the only one to be used in science. According to Føllesdal, Valløe & Elster (2001) the main point is that all our insight is hypothetic and tentative. This was also expressed by Pörn (1985), who maintains that within hermeneutics the hypothetic-deductive method applied to data comprising meaning with the overall aim to reveal the essence but to nomothetic science the aim is to create causality. However, qualitative description through induction may be a prerequisite or supplement for quantitative, deductive research and exploring complex phenomena not amenable to quantitative research, and vice versa (Pope & Mays, 1995; Morgan, 1998; Taylor 2002). Methodology is merely a question of tools to be used to facilitate the acquisition of knowledge, and the ideal in research is that the nature of the questions to be answered should determine the choice of approach (Nilstun, 1996; Hartman, 1998; Patton, 2002).

In this thesis, the different approaches and combination of methods used represent an attempt to maximize the possibility of gaining knowledge and understanding concerning living with long-term pain after a stroke (Brink & Wood, 1998; Morgan, 1998; Taylor, 2002).
Selection of participants (I-V)

The studies in this thesis concern patients who had been admitted during 1996 and 1997 to the Department of Neurology and Clinical Neurophysiology at a university hospital in Sweden. The patients were registered in the county area. The population in the catchment area for the hospital was approximately 170,000 (Statistics Sweden, 1996, 1997).

Patients were identified by means of an in-patient register, 2 years after an acute stroke incident. A total of 972 stroke patients with cerebral infarct or haemorrhage were registered at the clinic for 1996-1997. Patient selection was based on the Swedish version of the International Classification of Diseases (ICD), ICD-9 and ICD-10; Infarctus cerebri (433, 434/I63) and Hemorrhagia cerebri (431/I61). The diagnosis of stroke was defined in accordance with WHO (World Health Organization, 1989), excluding the subarachnoidal haemorrhages, based on clinical examination and computerized tomography (CT scan) within the first week after onset of symptoms. If the CT scan did not reveal a relevant cerebrovascular lesion (CVL), the localisation was based on clinical presentation only.

After 2 years, at the time of investigation, 356 (37%) of the 972 patients had died, which left 616 patients for investigation (Table 2). The inclusion criteria were an unequivocal stroke episode and long-term pain (>6 months) that occurred after the stroke. The exclusion criteria were other pain conditions and communicational impediments, which were the ones who were not independently able to take part in a conversation or answer the questionnaires. The selection procedure is shown in Table 2.

Included in all studies (I-V) were finally 43 persons with a diagnosed stroke, long-term pain that occurred after the stroke and no other major pain condition. Demographic data and stroke-related medical history are presented in Table 3.
Table 2. Selection procedure regarding the persons with long-term pain after a stroke

<table>
<thead>
<tr>
<th>Excluded, dropouts and included of total admitted 1996-1997</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number patients identified through in-patient records</td>
<td>616</td>
<td></td>
</tr>
<tr>
<td>Number excluded because of communicational disability</td>
<td>260</td>
<td>42.2</td>
</tr>
<tr>
<td>Impressive and/or expressive aphasia</td>
<td>84</td>
<td>32.3</td>
</tr>
<tr>
<td>Sight/hearing</td>
<td>11</td>
<td>4.2</td>
</tr>
<tr>
<td>Intellectual impairment</td>
<td>159</td>
<td>61.2</td>
</tr>
<tr>
<td>Non-Swedish-speaking</td>
<td>6</td>
<td>2.3</td>
</tr>
<tr>
<td>Number asked by mail</td>
<td>356</td>
<td></td>
</tr>
<tr>
<td>No answer</td>
<td>48</td>
<td>13.5</td>
</tr>
<tr>
<td>Decline</td>
<td>17</td>
<td>4.8</td>
</tr>
<tr>
<td>Number excluded after answering</td>
<td>245</td>
<td></td>
</tr>
<tr>
<td>No pain</td>
<td>151</td>
<td>61.6</td>
</tr>
<tr>
<td>Other pain conditions</td>
<td>94</td>
<td>38.4</td>
</tr>
<tr>
<td>Number included in the project</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>Died</td>
<td>1</td>
<td>2.2</td>
</tr>
<tr>
<td>Discontinued</td>
<td>2</td>
<td>4.3</td>
</tr>
<tr>
<td>Final study group for the project</td>
<td>43</td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Demographic data and stroke-related medical history of persons with long-term pain after a stroke

<table>
<thead>
<tr>
<th>Descriptive features</th>
<th>All (n=43)</th>
<th>Men (n=30)</th>
<th>Women (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years, Md (range)</td>
<td>66.0 (33-82)</td>
<td>64 (33-79)</td>
<td>76 (54-82)</td>
</tr>
<tr>
<td>Household status (number)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with partner</td>
<td>30</td>
<td>24</td>
<td>6</td>
</tr>
<tr>
<td>Living alone</td>
<td>9</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Living alone in sheltered home</td>
<td>4</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Working (number)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full-time</td>
<td>3</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Sick-leave part-time</td>
<td>5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Sick-leave full-time</td>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Early retirement/disability pension</td>
<td>10</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Old-age pension</td>
<td>24</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Stroke-related medical history (number)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previously healthy</td>
<td>8</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>26</td>
<td>17</td>
<td>9</td>
</tr>
<tr>
<td>Diabetic</td>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Cardiovascular disease and diabetic</td>
<td>8</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>
Data collection

All data collection was conducted in the home environment except when it came to the clinical examinations. Three investigators, the author and two physicians, performed the pain analysis and classification of pain independently, with 2-6 weeks between each investigation. Each of these investigations lasted approximately 1-2 hours (I). The data collection (I-V) was carried out in the following steps:

First data collection by the author included a qualitative interview about pain and pain experiences, and coping (III). Pain analysis was performed with the Pain-O-Meter (I). A structured interview on the basis of the ADL staircase was performed (II). Thereafter, the following postal questionnaires were answered by the participant within two weeks: supplementary questions from a Pain questionnaire (I), Self-report impairments, Assistive devices and the Multidimensional Pain Inventory-Swedish language version (MPI-S) (II)

Second data collection by a neurologist involved a general somatic and neurological examination including systematic medical and pain history, pain drawings and sensory and motor testing (I)

Third data collection by a physician involved thermal quantitative sensory testing (QST) (I)

Fourth data collection by the author, 2-3 month after the first, included a qualitative interview about health-related quality of life (IV) and experienced care (V). Thereafter, postal questionnaires were answered by the participant within two weeks: SF-36, and the Hospital Anxiety and Depression Scale (HAD Scale).

Quantitative investigations

The instruments included in the studies (I, II, IV), except for the Self-report impairment questionnaire have previously been psychometrically tested, which is being referred to in the presentation of the instruments. The data has been processed and analysed according to the guidelines or manuals of the instruments (I, II, IV).
Pain assessment (I, II)

The pain assessment was by means of pain analysis involving clinical examination and the answering of pain questionnaires. Pain analysis was performed by using the Swedish version of the Pain-O-Meter (POM) (Gaston-Johansson, 1996). Supplementary questions were selected from a standardized Pain questionnaire used in clinical practice covering pain duration and frequency together with factors affecting the pain, and pain treatment (Astra Läkemedel, 1993).

The POM combines the evaluation of pain characteristics in one tool making it possible to assess the sensation of pain intensity, by means of the visual analogue scale (VAS), and pain quality with the use of pain word descriptors from the McGill Pain Questionnaire, as well as localisation and frequency (Gaston-Johansson, 1996). The VAS scale in POM (POM-VAS) is a 10 cm vertical line with a movable marker, with “no pain” and “worst imaginable pain” assigned to the ends of the scale. A numerical 10 cm rating scale is located on the back of the POM, out of sight of the patient. The pain quality is measured by means of 12 sensory and 11 affective pain word descriptors (POM-WDS) in the Swedish version (Gaston-Johansson, 1996).

The participants described their pain localisation and the investigator marked the locations on an enlarged POM pain drawing chart in order to make it easier for the participants to participate. The POM-VAS rating was carried out by the participant by moving the marker along the line, and the rating was referred to the day of investigation. The decimals under/above 0.5 were rounded off to the nearest whole number. The POM-WDS were written enlarged and in extra bold type in separate columns for this investigation, and one column at a time was shown to the participants in order to make the words easier to distinguish. The participants chose the POM-WDS needed to describe the quality of their pain sensation for each pain localisation.

The frequency in POM is measured by whether the pain “is continuous” or “comes and goes,” which was asked and documented by the investigator (I). Psychometric testing of POM has been carried out in different pain populations. Satisfactory correlations were found between initial and repeat pain intensity ratings on the POM-VAS and POM-WDS (test-retest reliability). Concurrent and construct validity were also demonstrated (Gaston-Johansson 1996).
A clinical examination was performed at the hospital according to a protocol designed for the study. Pain history in relation to the stroke incident was ascertained by means of structured questions. Pain drawings were used for documentation of the pain locations. A general somatic and neurological examination was performed. The testing of sensory modalities included touch (cotton wool), cold (tuning fork at room temperature) and pinprick. The regions tested were cheek, arm, hand, leg, foot and trunk. The asymptomatic, contralateral side was used as a control. In motor testing, motor impairment was graded as mild, moderate or severe, and joint mobility as normal or limited. The medical history included prior diseases, current illnesses and the stroke event.

Long-term pain was classified in accordance to the criteria of the IASP (International Association for the Study of Pain, 1994) and tension-type headache according to the criteria of the Headache Classification Committee of the International Headache Society (IHS) (Headache Classification Committee of the International Headache Society, 1988). This means:

- Central pain; initiated or caused by a primary lesion or dysfunction of the central nervous system
- Nociceptive pain; pain due to actual and potential tissue damage
- Tension-type headache; associated with disorder of the pericranial muscles.

The brain injury was classified according to the location of the CVL and the clinical examination, as by Leijon, Boivie & Johansson (1989) (I).

Thermal quantitative sensory testing (QST) for cold, warmth and heat pain was performed in order to support the clinical classification of central pain using a modified Marstock thermostimulator operating on the Peltier principle (Thermotest, Somedic AB, Stockholm, Sweden) (Fruhstorfer, Lindblom & Schmidt, 1976; Boivie, Leijon & Johansson, 1989; Samuelsson, Samuelsson & Lindell, 1994). A thermal stimulus slowly increased or decreased from a neutral baseline and subjects indicated heat, warmth or cold pain thresholds by pressing a button. Thermal thresholds were obtained from the cheek, hand (thenar or hypothenar eminence) and lower leg (L5 dermatome) using the asymptomatic, contralateral side as a control. All examinations were performed by the same investigator with a thorough experience in performing
QST for clinical and scientific purposes (I). QST has been assessed as a dependable test to quantitatively evaluate cutaneous sensibility to warm, cold and thermal pain thresholds (Fruhstorfer, Lindblom & Schmidt, 1976; Arezzo et al., 1993; Yarnitsky et al., 1995). The technique of QST was also found to be clearly applicable to patients with brain lesions and central pain, and there was a good correspondence between quantitative and clinical findings (Boivie, Leijon & Johansson, 1989). The good repeatability of heat-pain threshold measurements performed by the Marstock method has been shown in earlier studies on stroke (Samuelsson, Samuelsson & Lindell, 1994).

The Multidimensional Pain Inventory-Swedish language version (MPI-S) is a 34-item self-report questionnaire, revised and adjusted to Swedish culture from a previously translated version (Carlsson, Bergström & Jensen, 1994) originating from the West Haven-Yale Multidimensional Pain Inventory (WHY)MPI (Kerns, Turk & Rudy, 1985). The instrument was designed for use in the case of chronic pain patients and purported to capture the multidimensionality of pain, and it is theoretically linked to the cognitive behavioural perspective on pain (Turk & Rudy, 1989). Section I of the MPI-S covers pain severity and cognitive-affective response to pain and comprises five scales (22 items): pain severity, interference, life control, affective distress and social support. Section II comprises three scales (12 items) and assesses the patient’s perception of responses from “significant others” to their display of pain and suffering: punishing responses, solicitous responses and distracting responses (Bergström et al., 1999). The respondents were asked to respond on a seven-point numerical scale (0-6), with higher scores indicating more of the characteristics in each of the items and scales, respectively, regardless of whether these are positively or negatively oriented (II). The psychometric analysis of the MPI-S used in this study has shown satisfactory results regarding its factor structure, reliability and generalizability (Bergström et al., 1998, 1999).
Disability (II)

Disability was investigated by means of two instruments. The ADL staircase was used in order to assess independence and dependence with regard to 10 activities of daily living in the form of a structured interview. The instrument is a development of the Katz ADL Index (Katz et al., 1963). Six items concern personal care (P-ADL): bathing, dressing, toileting, transfer, continence and feeding (Katz et al., 1963; Sonn & Hulter Åsberg, 1991). Four items concern instrumental ADL (I-ADL): cleaning, shopping, transportation and cooking (Sonn & Hulter Åsberg, 1991).

The ability to perform each activity is assessed on a three-grade scale: independent, partly independent, or dependent. The summarized scale is cumulative and graded from 0 to 10, and the higher the value, the greater the degree of dependence in ADL: Independent = grade 0; Dependent in I-ADL = grades 1-4; Dependent in I- and P-ADL = grades 5-10. In the case of to whom none of the grades applies, there is an additional category “Other”, signifying dependence in two or more activities but not classified as above. A prerequisite for a reliable result is that this category does not exceed 5%. The psychometric analysis of the ADL Staircase in a study on a general elderly population in Sweden has shown high reliability and validity. The discriminant validity was improved by inclusion of the instrumental activities (Sonn & Hulter Åsberg, 1991).

Screening of self-reported impairments was performed with a questionnaire designed for this study covering 14 types of common impairments after a stroke described in earlier research (National Board of Health and Welfare, 1999), with an additional question about pain. The impairments concerned: balance/vertigo, walking, shoulder/arm motion, hand/finger motion, sensibility, power of initiative, speech, swallowing, incontinence, concentration, memory, worry, low-spiritedness and emotional lability. The degree of experienced difficulty was indicated by the participants on a three-point numerical scale (0-3) as none, moderate or severe. “Other impairments” was given by means of an open-ended question lastly in the questionnaire.

Assistive devises were listed in a questionnaire designed for this study and covering commonly used devices in seven areas of the ADL staircase and out of
clinical experience. The persons were asked to list all the aids they were currently using and adjustments received concerning personal hygiene, dressing, bathroom, kitchen, entrances, mobility and transport.

Health-related quality of life (IV)

The study on HRQoL had a design combining quantitative and qualitative methods. Initially a qualitative interview was performed and thereafter the two questionnaires were answered. SF-36, a self-assessment instrument, constructed to achieve comprehensiveness with representation of multidimensional health concepts, including levels of well-being and personal evaluation of health, was to be answered first of the questionnaires (Ware & Sherbourne, 1992; Sullivan, Karlsson & Ware, 1995). SF-36 consists of eight scales comprising 35 items. An additional single item concerns health change over the past year. The scales concern physical functioning (10 items), role limitations due to physical problems (four items), bodily pain (two items), general health perceptions (five items), vitality (four items), social functioning (two items), role limitations due to emotional problems (three items) and mental health (five items). The respondent is asked about how the situation is now regarding all items of the physical functioning scale and the general health scale. Regarding all the other scales, the respondent is asked about how the situation has been during the last four weeks. The SF-36 scales are between 1-100, except “Health change.” Low scores indicate more physical, social and psychological influence on health-related quality of life. Low scores on the bodily pain scale indicate more influence of pain on HRQoL. SF-36 has shown satisfactory internal consistency and construct validity. The translation of SF-36 was performed by the International Quality of Life Assessment (IQOLA) Project Group into several languages, including Swedish. The Swedish version having been tested on a general population in Sweden has shown internal consistency and discriminant validity (Sullivan, Karlsson & Ware, 1995; Sullivan & Karlsson, 1998), also on stroke populations (Anderson, Laubscher & Burns, 1996; Dorman et al., 1998).

In order to complement the mental and emotional parts of SF-36, the Hospital Anxiety and Depression (HAD Scale) was included. The HAD Scale is a 14-item self-assessment mood scale concerning the person’s feelings during the last week.
It was constructed for use in the case of patients with somatic illness in non-psychiatric clinics, and is a screening instrument. The two subscales, anxiety and depression comprise seven items each, with a four-point verbal rating scale (0-3) and with summated scores ranging from 0 (no distress) to 21 (maximum distress). The cut-off levels on both subscales were used, with summated scores 0-7 as non-cases, 8-10 as doubtful cases and >10 as cases (Zigmond & Snaith, 1983). The HAD Scale has been found to be a valid bidimensional measure of mood disorders. This was confirmed by factor analysis, and there was an internal consistency in studies on stroke (Johnston, Pollard & Hennessey, 2000) and across different translations and somatic states (Zigmond & Snaith, 1983; Herrmann, 1997). In a recent literature review of psychometric data of the HAD Scale, including the Swedish version in six of the studies, the factor analysis demonstrated a two-factor solution in accordance with the HAD subscales anxiety and depression (Bjelland et al., 2002).

There were two dropouts on SF-36 and one excluded, and two dropouts on the HAD Scale.

**Statistical methods**

In all analyses, a level of $p<0.05$ was considered statistically significant.

The statistical analysis was performed using the software Statistical Package for the Social Sciences (SPSS) 10.0 (I, II) and 11.0 (IV).

All data was treated as non-parametric data because none of the data was normally distributed and the samples were small (I-V). Non-parametric data was presented as frequencies (I-V) and/or percentages (I, II, III), median, range (I) or quartiles (IV).

In order to compare the results of the MPI-S with previous studies, the descriptive data was presented as mean and standard deviation (SD) (II).

Non-parametrical statistical tests used were Spearman’s coefficient of correlation, Mann-Whitney $U$-test and Kruskall-Wallis for group comparison of independent samples. Wilcoxon’s signed-rank test was used when data was paired, i.e. to statistically compare thermal thresholds (QST) on the affected and non-affected sides (asymptomatic, contralateral) (I). Cronbach’s $\alpha$ coefficient was used to analyse the
internal consistency, i.e. homogeneity, of the scales in MPI-S (II) (Nunnally & Bernstein, 1994; Streiner & Norman 1995).

**Qualitative investigations**

Three studies included in this thesis were based on qualitative data (III, IV, V). The data collections performed were based on an interview guide for each area (III, IV, V). The interviews started with an open-ended question, without time limitation in order to enhance the participants’ ability to communicate their experiences as comprehensively as possible. Thereafter the interviews were in the form of a conversation, whereby follow-up questions were asked to ensure that the participants described their pain experience. All interview data was tape-recorded and transcribed verbatim, including expressions of emotion.

**Pain experience (III)**

The first data collection started with an interview covering two areas. Initially, the participants’ pain and pain experiences were investigated by asking them to describe both their pain and pain experience as comprehensively as possible. There was a break after this interview area.

**Coping (III)**

At the start of the second interview area at the first data collection, the participants were asked, “How do you cope with your pain?” Follow-up questions were asked when necessary concerning how the participants used coping efforts with regard to actions, thoughts and feelings. The two interview areas during the first data collection lasted approximately 45 minutes each.

**Health-related quality of life (IV)**

The qualitative investigation regarding HRQoL was based on the question, “How would you describe your quality of life, especially in relation to your pain?” This was the first area of the interview during the fourth data collection, and this part lasted a
minimum of 30 minutes (IV). There was a break after this interview area, when the participant was given time to rest.

**Caring (V)**
This interview area concerned the 43 participants’ experiences of their care. They were asked to describe their experiences as comprehensively as possible, and the interview question was: “Please tell me how you have been treated, especially in relation to your pain.” This interview area lasted a minimum of 45 minutes.

**Qualitative analysis**
All the interview data were analysed inductively by means of latent content analysis, also called qualitative content analysis (III, IV, V) (Polit & Hungler, 1999). Content analysis focuses on human communications and is suited to research that involves eliciting meaning, interpretations, consequences and contexts (Downe-Wamboldt, 1992; Morse & Field, 1995). Content analysis has many methods depending on the purpose of the study and the nature of the narrative data (Lieblich, Tuval-Mashiach & Zilber, 1998) and therefore it is necessary to clarify the actual procedures.

The recorded tapes for each area of investigation were re-listened to before the analysis and naively read through several times, for each person, in order to gain a sense of the context. The analysis involved a systematic process of identifying the patterns of meaning in the context. All the units of meaning relevant to the research question were labelled. As much variety of experiences as possible were included in the analysis. The emerging patterns of the areas on the basis of experience obtained were grouped and classified into categories and themes. Thereafter, the themes and categories were scrutinized several times for their content as well as their relevance to the context. During the various steps of the analysis, the interview data and the analysis were read by one or two co-assessors and the results were discussed together until agreement was reached (Lieblich, Tuval-Mashiach & Zilber, 1998; Patton, 2002).

In addition to latent content analysis, manifest content analysis was used in the final steps of one study because of the differences obtained when reading and analysing the data (III) (Morse & Field, 1995; Polit & Hungler, 1999; Patton, 2002).
In one study (V), the most information-rich interview data, which came to be the data of 23 participants, was selected for further and deeper analysis on the basis of the feeling of congruence when reading all the 43 interviews. This data was classified and scrutinized for its content and its relevance to the context. Thereafter, all 43 interviews were read again in order to scrutinize the overall congruence (Lincoln & Guba, 1985; Patton, 2002).

**Ethical considerations**

All studies in this thesis were conducted in accordance with the World Medical Association Declaration of Helsinki (MRF, 2000), and ethical approval was obtained from a regional ethical research committee at a university hospital in Sweden (I-V).

Autonomy was implemented by giving all potential participants an autonomous choice regarding whether to participate. Information was given in writing and orally. It was made clear that participation was voluntary and could be terminated at any time, and that confidentiality was assured. Thereafter the ones who were willing to participate gave their written informed consent, which preceded the data collection. All participants were legally competent to personally give their consent. None of the participants had a dependent relationship with any of the investigators that could have influenced the participation or the results. They were informed about the clinical investigations at the hospital and asked to suggest where the other investigations could take place. A place for privacy, without interruptions, was obtained for the interviews. The principles of beneficence and nonmaleficence are important and guided the design and data collection. Before all steps in the data collection, the participants were contacted by the author. They were thoroughly informed and asked about their willingness to continue to participate, and given the possibility of declining participation or discussing any obscurities. Adequate time of 1-2 hrs was provided for each investigation, i.e. the clinical examinations and the ones in their homes. The participants were provided with telephone numbers for further contact with all the investigators. Information regarding the results of examinations performed was given orally. The principle of justice should be seen in the light of the possibility of
obtaining new knowledge and understanding that may improve the care of persons with long-term pain after a stroke.

RESULTS

Pain description and pain experience
The clinical classification of pain revealed three types of pain among the 43 participants. Fifteen participants, aged 32-80 years (Md 65.0) were classified as having central pain, eighteen, aged 33-82 years (Md 70.0) as having nociceptive pain in the stroke-affected body side, and ten, aged 48-82 years (Md 66.0) as having tension-type headache, with debut at the time of or after the acute stroke incident. Four participants had two types of pain according to the clinical classification (central and nociceptive). Two of them were with the support of QST classified as having central pain, and the two others as having nociceptive pain. In the participants classified as having central pain, the thermal sensibility for all modalities was significantly reduced on the symptomatic side on all sites measured (p<0.01) (I). The location and type of CVL and types of pain are shown in Table 4.

Table 4. Location and type of cerebrovascular lesion (CVL) in persons with long-term pain after a stroke (n=43)

<table>
<thead>
<tr>
<th>Location of CVL</th>
<th>Type of CVL</th>
</tr>
</thead>
<tbody>
<tr>
<td>BS</td>
<td>TH</td>
</tr>
<tr>
<td>Central pain (n=15)</td>
<td>2</td>
</tr>
<tr>
<td>Nociceptive pain (n=18)</td>
<td>2</td>
</tr>
<tr>
<td>Tension-type headache (n=10)</td>
<td>1</td>
</tr>
</tbody>
</table>

BS = brainstem; CVL located in medulla oblongata, pons and midbrain. TH = thalamus; CVL affecting the thalamus. SE = supratentorial, extrahalamic; CVL not affecting the thalamus. TH/SE = supratentorial; CVL including affecting the thalamus. UI = unidentified; CVL location based on clinical examination only.

Inf = infarcts, Hem = haemorrhagia
Twenty-eight (28/43) did not know the cause of their pain, proportionally most participants with tension-type headache (I) and in the interview, incomprehensibility emerged as one pain-related problem, due to their lack of knowledge and understanding of the pain (III).

At the time of investigation, 2 years after the stroke incident, the mean duration of pain in all was 20 months. The pain was reported to be worse in twelve (12/43), and five (5/18) with nociceptive pain reported an extended pain location (I). Pain caused significantly more difficulty among the older age group, ≥60 years (p<0.05), than the younger (II). Location and distribution of pain was contralateral to the CVL lesion in all participants with central or nociceptive pain (I).

Thirty-nine (39/43) considered it easy to describe their pain location. Eight with central pain (8/15) had hemipain, except in the face in four of them. The other seven with central pain had pain in the limbs, part of the limbs, hand and/or digits or lateral side of the foot. Among participants with nociceptive pain, nine (9/18) had pain in the shoulder/upper arm or shoulder only, and eight in the shoulder/arm or in the shoulder/arm/hand. One participant had nociceptive pain in the lower part of the lower leg only due to spasticity. Four (4/10) with tension-type headache had pain in the crown and half of the head, and the other six either in the crown and occiput or the crown only (I, III).

Among the participants with nociceptive pain three (3/18) were estimated as having a frozen shoulder, three as having subluxation, two as having both frozen shoulder and subluxation, and ten as having non-specific muscular pain. Three of them were spastic in the shoulder/arm or leg only. Five had decreased joint mobility in the shoulder/arm (I).

Allodynia for touch and/or cold was found among participants with central or nociceptive pain. Hypoalgesia for pin-prick was found among participants with central or nociceptive pain. Hyperalgesia for pin-prick was found among participants with central pain or tension-type headache (I).

Pain onset, intensity, quality and frequency are shown in Table 5. The median values of the pain intensity were similar in the pain groups, but individual differences among the participants emerged within the groups as shown in the range. The highest
pain ratings (POM-VAS; 9-10) were by two hemiplegic participants (I). A great deal of variation emerged in the interviews with regard to pain intensity and the pain was described as dull to the worst imaginable (III). Eight (8/15) of the participants with central pain reported moderate and seven of them severe pain. Among participants with nociceptive pain eleven (11/18) reported moderate and seven severe pain (II), and among those with tension-type headache eight (8/10) reported moderate and two severe pain (II). The sensory pain descriptors used most frequently by participants with central pain were burning, aching, dull and stabbing (I), also cutting and numbness (III). In participants with nociceptive pain it was cramping (I), dull and gnawing (III), and in tension-type headache it was pressing (I), stubbing or heaviness in the head (III). The common affective pain descriptors overall were troublesome (I, III), annoying and tiring (I) and participants with tension-type headache also reported worrying and terrifying (I, III).

Table 5. Types of pain and pain characteristics in persons with long-term pain after a stroke (n=43)

<table>
<thead>
<tr>
<th>Pain onset after the acute stroke incident (number):</th>
<th>Central pain (n=15)</th>
<th>Nociceptive pain (n=18)</th>
<th>Tension-type headache (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 week</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>1 week-1 month</td>
<td>3</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>2-6 months</td>
<td>7</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>20-27 months</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>POM-VAS and POM-WDS, Md (range):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain intensity</td>
<td>6.0 (4-10)</td>
<td>4.5 (3-9)</td>
<td>5.0 (3-8)</td>
</tr>
<tr>
<td>Number sensory pain descriptors</td>
<td>2.0 (1-4)</td>
<td>2.0 (1-4)</td>
<td>1.5 (1-3)</td>
</tr>
<tr>
<td>Number affective pain descriptors</td>
<td>2.0 (1-3)</td>
<td>2.0 (1-4)</td>
<td>2.0 (1-3)</td>
</tr>
<tr>
<td>Frequency (number):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continuously, never free from pain</td>
<td>6</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Continuously, free from pain for an hour or so, after treatment, medicine or rest</td>
<td>2</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Almost every day, maybe completely free from pain some days</td>
<td>4</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Almost every week, maybe completely free from pain some weeks</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Comes and goes</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>
In the interviews the participants described themselves as more irascible and angry than usual since the pain was disheartening or enervating. All participants with tension-type headache described distress due to fear or anxiety, especially concerning whether a new clot was forming when they had a headache (III). Incomprehensibility, because of lack of knowledge and understanding of the relation between the stroke and their pain, of the cause of the pain, the prognosis, or available treatment, was also commonly described (III). Participants with central or nociceptive pain spoke of disturbed sleep as a major problem because of difficulty in finding a comfortable body position at night due to their pain. They also experienced diminished physical capacity in daily life due to their pain, proportionally more than the ones with tension-type headache who experienced more difficulty regarding concentration and memory (II, III). Stress in relationships was more frequently described by those with tension-type headache than by the others. Pain was reported to be tiring (I) and fatigue was commonly described by the participants with tension-type headache and the ones with continuous pain (III). The frequency of pain-related problems was equal in the case of gender and the age groups, 33-64 years (n=19), and 65-82 years (n=24) (III).

The most common factors increasing the pain in participants with central pain were cold, touching (I, III), windy conditions and temperate water, static body positions (III) and stress/anxiety (I). In the case of nociceptive pain it was lifting, physical movements, cold, touching (I), physical exertion and lying on the stroke-affected side (III). In the case of tension-type headache it was stress/anxiety (I) and stress associated with time pressure or too many activities (III). In all, the most common factors decreasing the pain were medicine, rest and peace and quiet (I, III). Additionally, a change of body posture decreased the pain in fourteen (14/18) by those with nociceptive pain (I), as also emerged in the interviews (III).

Sixteen (16/43) of the participants reported no prescribed pain medication, even though more than half of the participants with central or nociceptive pain suffered from pain continuously or nearly continuously (Table 5) (I, III). Nine (9/43) used prescribed medication regularly and eighteen (18/43) when necessary. Five (5/15) with central pain had been prescribed amitriptylin or tramadol with various effects. Eight others with central pain were prescribed pain medication such as dextropropoxifen,
paracetamol or acetyl acid on their own or in combinations without obtaining pain relief (I). Four (4/18) with nociceptive pain were prescribed pain medication, and six (6/10) with tension-type headache took medication on their own when necessary (I, III). Discontinuing of prescribed medication (III) was because of insufficient pain relief, side-effects or fear of side-effects (III). Other treatments, such as transcutaneous electrical nerve stimulation (TENS), gave some participants pain relief or satisfaction (I, III, V) but the ones treated had been requested to return the equipment because others needed it even though they experienced it as positive (III). Some of the participants who had tried QiGong, acupuncture and massage (I) were satisfied even though they did not always obtain pain relief (III).

No significant differences were found between age, gender or the types of pain and the MPI-S scales (II). Regarding the reliability analysis of the MPI-S, the \( \alpha \) values of all scales were satisfactory, except for the scales life control \( \alpha 0.68 \), affective distress \( \alpha 0.49 \) and interference \( \alpha 0.94 \) (II).

In summary, in most of the participants the pain onset was within six months after the stroke incident and reported to be stable since then. Continuous pain or pain almost every day was reported by nearly two-thirds. Nearly all found it easy to describe the pain location, and the participants spoke in detail about their pain, even though the pain was incomprehensible to most of them, due to lack of or comprehensible information and knowledge. When it came to pain intensity on the basis of the structured questions as well as the interviews, there emerged individual differences among the participants. Pain quality was described in similar ways but also distinctively for each pain condition, as burning and numbness by participants with central pain, cramping by participants with nociceptive pain and pressing by participants with tension-type headache. The pain was mostly described as troublesome, annoying and tiring in all groups, also as worrying, but mostly by participants with tension-type headache. The factors increasing the pain most in participants with central or nociceptive pain was physical strain and exertion as well as cold and touching, and stress/anxiety in participants with tension-type headache. Some pain relief was obtained through peace and rest, medication, by changing body posture, and a few through treatments such as TENS.
Disability

Nine (9/43) participants had severe motor impairment such as hemiparesis, five had moderate, and twenty-nine mild paresis. Eighteen (18/43) of the participants had spasticity (I). Twenty (20/43) were dependent according to the ADL staircase; nine only in I-ADL (grades 1-4), nine in I- and P-ADL (grades 5-10) and two other were also dependent but not classifiable. Proportionally the participants with nociceptiv pain were most dependent in ADL and on assistive devices. One-third of the independent participants were using assistive devises in their daily life. The most commonly used assistive devices concerned mobility and the bathroom. Twenty-two (22/43) were dependent on assistive devices for moving indoors, and twelve for transportation outdoors. Twenty participants used one to four technical aids in the bathroom (II).

Differences were found between the age groups, i.e. 33-59 years mainly working and 60-82 years on full-time retirement, with significantly more difficulty in shoulder/arm motion and continence (p<0.05) in the older age group. No significant differences were found between the participants with regard to the different types of pain, nor gender. Proportionally participants with nociceptive pain had more difficulty in mobility and/or motion-related activities than others. The participants with tension-type headache experienced proportionally least difficulty with regard to impairments as compared with the others, apart from in concentration, memory and worry (II) (Table 6). Diminished mental capacity emerged also in the interviews of the participants with tension-type headache (III) and worry (I). Low-spiritedness was reported by half of the participants with central or nociceptive pain and a third of the participants with tension-type headache (II). The proportion was approximately the same regarding emotional lability (II). Also, the power of initiative had decreased in approximately half of all.

As a result of the open-ended question, twenty-one (21/43) reported decreased shoulder/arm and hand/finger function, which had forced these participants to perform daily physical activities with the other, unaffected arm/hand.

Four (4/43) were living in sheltered homes, three had day-care and one home-nursing care. Twelve received daily help from their spouse/partner, and help from other relatives was received by twenty-three participants everyday (II, V).
Table 6. Self-reported impairments in relation to type of pain in persons with long-term pain after a stroke (n=43)

<table>
<thead>
<tr>
<th></th>
<th>Moderate and severe difficulty</th>
<th>Central pain (n=15)</th>
<th>Nociceptive pain (n=18)</th>
<th>Tension-type headache (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>number</td>
<td>%</td>
<td>number</td>
<td>%</td>
</tr>
<tr>
<td>Balance/vertigo</td>
<td>11</td>
<td>73%</td>
<td>14</td>
<td>78%</td>
</tr>
<tr>
<td>Walking</td>
<td>12</td>
<td>80%†</td>
<td>17</td>
<td>94%‡</td>
</tr>
<tr>
<td>Shoulder/arm motion</td>
<td>10</td>
<td>67%†</td>
<td>17</td>
<td>94%‡</td>
</tr>
<tr>
<td>Hand/finger motion</td>
<td>11</td>
<td>73%†</td>
<td>13</td>
<td>72%‡</td>
</tr>
<tr>
<td>Sensibility</td>
<td>12</td>
<td>80%*†</td>
<td>10</td>
<td>56%</td>
</tr>
<tr>
<td>Power of initiative</td>
<td>9</td>
<td>60%</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>Speech</td>
<td>1</td>
<td>7%</td>
<td>8</td>
<td>44%*</td>
</tr>
<tr>
<td>Swallowing</td>
<td>3</td>
<td>20%</td>
<td>6</td>
<td>33%</td>
</tr>
<tr>
<td>Incontinence (urinary)</td>
<td>5</td>
<td>33%</td>
<td>8</td>
<td>44%</td>
</tr>
<tr>
<td>Concentration</td>
<td>9</td>
<td>60%</td>
<td>7</td>
<td>39%</td>
</tr>
<tr>
<td>Memory</td>
<td>9</td>
<td>60%</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>Worry</td>
<td>7</td>
<td>47%</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>Low-spiritedness</td>
<td>8</td>
<td>53%</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>Emotional lability</td>
<td>6</td>
<td>40%</td>
<td>10</td>
<td>56%</td>
</tr>
</tbody>
</table>

1 = 1 missing  
2 = 2 missing

* = Comparison between central and nociceptive pain, p<0.05
† = Comparison between central pain and tension-type headache, p<0.05
‡ = Comparison between nociceptive pain and tension-type headache, p<0.05
§ = Comparison between nociceptive pain and tension-type headache, p <0.001

In summary, most of the participants had various degree of difficulty with regard to mobility and/or motion-related activities, and significantly more in the older age group with regard to shoulder/arm motion and incontinence. Nearly half were dependent on others in ADL and on assistive devices, mostly participants with nociceptive pain. In approximately half low-spiritedness, emotional lability, decreased power of initiative, and/or worry were reported. Proportionally, reported participants with tension-type headache more difficulty in concentration, memory and worry than others.

Coping

The results, deriving from the inductive approach, reveal that the coping strategies described were both problem- and emotion-focused, but most often problem-focused (Table 7). Apart from the emotion-focused coping strategy making the pain
comprehensible, various problem-focused efforts to avoid and/or to relieve the pain
were described. The planning strategy was related to stress experiences regarding
physical activities described by participants with central or nociceptive pain, whilst
among the ones with tension-type headache it was mentally stressful events. Changing
of body position day and night, and by using the other hand/arm when they were in
pain, was also described by participants with central or nociceptive pain. Various
physical exercises such as stretching and aquatic exercise and massage and, were
described by participants with central or nociceptive pain. Taking or having taken
medications was reported in all groups. Non-prescription analgesics were common and
taken when necessary or at night in an attempt to relive the pain. These were
sometimes taken in combination with prescribed medication. A few took sleeping aids
or analgesics before engaging in social activities (III).

Communicating with professionals and next of kin by asking, complaining or
telling about their pain was described by nearly all participants (Table 7). Distraction
through thinking about something else than the pain or doing something else were
applied. One common emotion-focused strategy described was making comparisons
between before and after the stroke incident, between what happened and might have
happened, such as losing their ability to talk, and others who had suffered a stroke.
Enduring the pain was described by approximately half in each group (III).

Both negative and positive outcomes of coping were described. The negative
outcomes were similarly described by all. The negative outcome was perplexity and
resignation. The participants spoke of their attempts to communicate about their pain
without receiving sufficient response, being confronted with the professionals’ lack of
knowledge or other care givers’ when they had asked for help. The participants’
frustrations about insufficient pain relief were manifest in the interviews, as were
frustrations about not being given consideration when they complained about their
pain. Also a source of frustration was that members of their family sometimes
responded evasively when they talked about their pain, and their inability to help left
the participants with a feeling of loneliness. The positive coping outcome was short-
term pain relief or satisfaction from various treatments or from receiving attention and
considerateness (III).
Table 7. Coping strategies used by persons with long-term pain after a stroke (n=43)

<table>
<thead>
<tr>
<th>Categories and subcategories</th>
<th>Central post-stroke pain (n=15)</th>
<th>Nociceptive pain (n=18)</th>
<th>Tension-type headache (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>number (%)</td>
<td>number (%)</td>
<td>number (%)</td>
</tr>
<tr>
<td>Making the pain comprehensible</td>
<td>10 (67)</td>
<td>14 (78)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Effort to avoid and to relieve pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning</td>
<td>9 (60)</td>
<td>17 (94)</td>
<td>7 (70)</td>
</tr>
<tr>
<td>Changing body position</td>
<td>9 (60)</td>
<td>16 (89)</td>
<td>–</td>
</tr>
<tr>
<td>Physical exercise</td>
<td>4 (27)</td>
<td>4 (22)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Massage</td>
<td>6 (40)</td>
<td>3 (17)</td>
<td>–</td>
</tr>
<tr>
<td>Taking medication</td>
<td>9 (60)</td>
<td>16 (89)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Discontinuing medication</td>
<td>3 (20)</td>
<td>4 (22)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Communicating</td>
<td>13 (87)</td>
<td>18 (100)</td>
<td>9 (90)</td>
</tr>
<tr>
<td>Making comparisons</td>
<td>9 (60)</td>
<td>10 (56)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Distractions</td>
<td>11 (73)</td>
<td>12 (67)</td>
<td>5 (50)</td>
</tr>
<tr>
<td>Rest and relaxation</td>
<td>3 (20)</td>
<td>7 (38)</td>
<td>7 (70)</td>
</tr>
<tr>
<td>Warming oneself</td>
<td>6 (40)</td>
<td>5 (28)</td>
<td>–</td>
</tr>
<tr>
<td>Stopping activities</td>
<td>–</td>
<td>5 (28)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Enduring the pain</td>
<td>9 (60)</td>
<td>10 (56)</td>
<td>4 (40)</td>
</tr>
<tr>
<td>Acceptance</td>
<td>2 (13)</td>
<td>7 (38)</td>
<td>5 (50)</td>
</tr>
</tbody>
</table>

In summary, the participants used a number of problem- and emotion-focused coping strategies, but the problem-focused most often. Various efforts to avoid and/or relieve their pain were described. Nearly half of all were enduring their pain, and the acceptance of their pain was low. Communicating the pain was the most frequently used strategy but their efforts often left the participants with a feeling of perplexity and resignation. This was related to their experience of the professionals’ lack of knowledge, and to attention and sufficient pain relief. On the other hand, satisfaction was described in the cases of consideration shown by others and/or short-term pain relief.
Health-related quality of life

The qualitative data revealed what the participants evaluated as influencing their health-related quality of life. Three areas relating to physical aspects emerged, which were freedom from pain, having physical and cognitive capacity, and physical independence. The psychological aspects concerned also three areas, and were well-being, contentment and experienced freedom. Well-being was in the form of being able to retain self-esteem and share a cheerful atmosphere with others. Contentment meant being content with one’s life despite altered living conditions. Experienced freedom was with regard to time and freedom to be able to choose activities as well as living conditions. The aspects relating to occupation had to do with two areas, employment and leisure time. The meaningfulness of employment for the ones who were still working was described, and brought some change in their daily life. Leisure time meant being occupied and having the capacity for and possibility of participating in different leisure activities such as nature, society and club activities and hobbies. Social and economic aspects concerned three areas, which were good family and relationships, social intercourse and economic security. The importance of family and relationships that work and of one’s home environment was described. It was related to experienced comfort and support from their family in the form of considerateness and practical care. Furthermore, the social intercourse included their ability and possibility of being together with family and friends. Economic security had to do with economic independence and thereby the possibility of engaging in activities such as travelling (IV).

The results in respect of health-related quality of life according to SF-36 and mood disorders according to the HAD Scale are shown in Table 8. No significant differences were found with regard to the types of pain on either SF-36 or the HAD Scale. Therefore the participants are presented as one group (Table 8) (IV).

Significant differences were found in SF-36 when comparing the two age groups, i.e. <65 years, of working age and >65 years with old-age pension, in physical functioning with more decreased function in the older age group (p<0.05). The men had more decreased vitality (p<0.05) than the women (IV).
Table 8. Health-related quality of life and mood in persons with long-term pain after a stroke

<table>
<thead>
<tr>
<th>SF-36 scales and HAD Scales</th>
<th>Q₁</th>
<th>Median</th>
<th>Q₃</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36 (n=40)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>20.0</td>
<td>47.5</td>
<td>73.8</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>0.0</td>
<td>25.0</td>
<td>93.8</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>32.0</td>
<td>41.0</td>
<td>58.5</td>
</tr>
<tr>
<td>General Health</td>
<td>37.8</td>
<td>50.0</td>
<td>67.0</td>
</tr>
<tr>
<td>Vitality</td>
<td>31.3</td>
<td>45.0</td>
<td>70.0</td>
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<tr>
<td>Social Functioning</td>
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<td>62.5</td>
<td>87.5</td>
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<tr>
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<td>50.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Mental Health</td>
<td>48.0</td>
<td>74.0</td>
<td>88.0</td>
</tr>
<tr>
<td>Health change during the past year (scores 1-5)</td>
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<td>3.0</td>
<td>3.0</td>
</tr>
<tr>
<td>HAD Scale (n=41)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total scale</td>
<td>5.0</td>
<td>10.0</td>
<td>17.5</td>
</tr>
<tr>
<td>Anxiety subscale</td>
<td>2.5</td>
<td>5.0</td>
<td>8.5</td>
</tr>
<tr>
<td>Depression subscale</td>
<td>1.5</td>
<td>4.0</td>
<td>19.0</td>
</tr>
<tr>
<td>Anxiety (number)</td>
<td></td>
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</tr>
<tr>
<td>Non cases</td>
<td>0-7</td>
<td></td>
<td>27</td>
</tr>
<tr>
<td>Doubtful cases</td>
<td>8-10</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Cases</td>
<td>&gt;10</td>
<td></td>
<td>2</td>
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<tr>
<td>Depression (number)</td>
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<tr>
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</tr>
<tr>
<td>Cases</td>
<td>&gt;10</td>
<td></td>
<td>6</td>
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</table>

Q₁ = the 25th percentile, Q₃= the 75th percentile

No significant differences were found on the HAD subscales with regard to demographic data. Six of the eight participants (8/41) who scored >10 on the HAD subscales were men, of older age, and five were living with a partner, dependent on others (IV).

In summary, the interviews revealed what the participants evaluated as health-related quality of life with reference to their present situation. Freedom from pain and being independent and occupied with things of interest were important aspects of it, as were having good relationships and support from family and friends and the ability of being together, as well as economic security. The results of their health-related quality according to SF-36, the participants’ physical role and pain were most influenced. More than half reported no anxiety or depression.
Caring
Themes of experienced positive and negative dimensions of care emerged in the interviews with regard to pain and to the care in general by professionals and next of kin. The positive aspects of care were in this study the ones the participants experienced as helpful and satisfying, having to do with being in a situation of caring. The negative were the ones experienced as disappointing and discouraging, having to do with being in a situation of uncaring. Most of the participants were seldom in touch with a doctor or other professionals (V).

Being in a situation of caring, with regard to pain, was experienced when the participants were treated seriously and understood by the professionals. This was when the professionals made an effort to listen, understand and provide pain relief, and when the participants received answers to their questions related to their pain. Further, when they experienced temporary pain-relief from prescribed medication after their complaints. Satisfaction was experienced as a result of other treatments offered by the professionals, as aquatic exercise and TENS. Receiving help in changing their body position at night and advice about specific alternate body positions or movement in order to avoid pain were considered as caring. Experienced caring on the part of their next of kin, with regard to pain, was when the participants were shown thoughtfulness. This was in the form of receiving attention and practical help, getting advice about obtaining pain relief, and when their next of kin tried various forms of distraction and when they were having fun together (V).

Experienced caring, with regard to the care in general as provided by the professionals was in terms of being encouraged by the professionals’ manner, being confident in the professionals’ competence, being informed and being given continuity in the professional contact. It was positive when they experienced the professionals as nice, jolly and humorous, and they spoke of confidence in the professionals’ competence when they experienced that the professionals had requisite knowledge and a holistic view of their situation. Being informed had to do with the professionals’ thoughtful and honest way of informing about the diagnosis, treatment and prognosis, and the thorough instructions and continuous supervision received during the rehabilitation. Experienced caring on the part of their next of kin was a question of
receiving practical and emotional support. They appreciated being taken out for a walk or a ride or just being together (V).

Being in a situation of uncaring was what emerged most strongly in the interviews. Uncaring, with regard to pain, was commonly experienced because of professionals’ lack of knowledge and understanding. Being ignored was experienced in situations when they complained about their pain, as during physical exercise. They spoke of insufficient analgesics received and lack of follow-up of analgesics prescribed, as well as incomprehensible answers to their questions about the pain. Lack of understanding was experienced because of not receiving attention and not being believed when they talked about their pain. Further, they experienced a sense of superiority on the part of professionals when they tried to talk about pain treatment. Experienced uncaring, by next of kin, was lack of support and loneliness in close relations. This related in the interviews to their next of kin’s lack of knowledge about what to do regarding their pain or because of their own ill-health (V).

Experienced uncaring, with regard to their care in general, concerned both the professionals and next of kin because of not being understood. The participants experienced that the other’s understanding was considered, not their own. They also experienced the professionals’ lack of sensitivity to their difficulties, and spoke of receiving incorrect negative statements about the prognosis. Lack of acknowledgement was experienced in terms of insufficient attention and time, commonly described during their encounters with the professionals. Lack of adequate information concerned what the participants described as absent, contradictory or incomprehensible. They also described lack of accessibility and continuity. This pertained to the difficulty of getting in contact with the professionals by telephone and making appointments, delayed appointments, and delay and uncertainties about treatment promised by the doctor or physiotherapist. Lack of continuity had to do with difficulty in seeing the same doctor, and the many changes among the personnel. Lack of participation was experienced because of difficulty in choosing the doctor they have confidence in or in getting more frequent exercise under the supervision of a physiotherapist (V).
In summary, the most prominent experiences were the ones having to do with being in a situation of uncaring. The results reveal several areas of need in respect of what the participants consider necessary for the achievement of proper care. First, is the need of professional knowledge about pain and pain management. Second, there is the need of sufficient communication, being respected and understood, the need of support and encouragement. Third, there is the need of accessibility, sufficient time and continuity in the professional contacts.

DISCUSSION

Discussion of the results
This thesis is the first to include three long-term pain conditions after a stroke in the same studies. There are few interview studies concerning the experiences of stroke as compared with all the quantitative studies in the literature, and none previously on the experiences of the pain, nor has there been any on the influence of long-term pain on the persons’ life situation and how they manage their pain and are being cared for. The results from the quantitative (I, II, IV) and the qualitative investigations (III, IV, V) were complementary.

The pain was classified in the 43 participants included. The classification (I) corresponded with previous studies on central pain (Leijon, Johansson & Boivie, 1989; Andersen et al., 1995), shoulder pain (Jespersen et al., 1995; Turner-Stokes-Jackson, 2002) and tension-type headache (Vestergaard et al., 1993). Four participants suffered from two types of pain, central and nociceptive, and all except one of those with nociceptive pain had shoulder pain. The fact that some persons may suffer more than one type of pain after a stroke has previously been reported by Bowsher (1995) and Boivie (1999).

It is noticeable that the participants had suffered their pain for on average nearly two years, most of them every day without knowing the reason for it (I) although they had tried to communicate with the professionals about it (III, V). This means that their pain had probably not been adequately assessed and/or that when they were prescribed
treatment it was insufficient and/or not adequately followed up (I, III, V). This is reported to be a common problem in persons suffering from long-term pain (McCaffery & Ferrell, 1997; Carr, 2002; Jensen & Baron, 2003). It is a basic requirement to classify pain following a stroke in order to prevent suffering and offer adequate treatment and care (Turner-Stokes & Jackson, 2002; Jensen & Baron, 2003).

There is available pharmacological treatment for central/neuropathic pain, but it is still considered as a condition difficult to treat because of the nature of the pain and of side-effects of medication. A recent literature review reveals that moderate pain relief is found only in one-third of patients with central/neuropathic pain regardless of underlying disease (Jensen & Baron, 2003). Other and/or complementary individually tailored treatment options and a good supportive care have to be included in the management of central pain (Vestergaard et al., 2001; Ahmad & Goucke, 2002).

Even though there are analgesics for nociceptive pain, the participants in this thesis used mainly non-prescribed medication such as paracetamol, with insufficient pain relief. One of the questions emerging from the results is whether the participants had previously been given enough attention and were adequately examined since the clinical examination revealed subluxations, frozen shoulders and spasticity (I). Shoulder pain, the most common type of pain following stroke, is however still reported to be a problem within care and rehabilitation, because of lack of knowledge, prevention, and there is no answer which treatment is most effective (Rice, 2002; Ratnasabapathy, et al., 2003).

In most long-term pain conditions it may be a long time before a person obtains pain relief, therefore thorough information and follow-up is important (Jacobson & Mariano, 2001). The participants were worrying about their pain (I), which also reveals the need of comprehensive and recurrent information.

The pain-related problems described have been previously reported in studies on long-term pain (Jensen & Lenz, 1995; Craig, 1999), which support the findings with regard to the distinctions made by the participants between their pain and other consequences of stroke (III). Incomprehensibility was described, which remains common among persons with long-term pain, especially when they lack knowledge and the pain origin is considered mysterious (Aldrich, Eccleston & Crombez, 2000;
Jensen et al., 2003). Participants with central and nociceptive pain had disturbed sleep because of difficulty in finding a comfortable body posture or a need to change their body position during night. It is especially important to take account of this in the care of hemiplegic and paretic patients (Dowswell, Dowswell & Young, 2000).

The results revealed, compared with other studies, relatively few with mood disorders according to the HAD Scale. This was supported by the results from the mental health scale in SF-36, which also showed relatively little influence of mood on their HRQoL (IV).

In the interviews, mood changes were the most frequently described pain-related problem and reported by all with tension-type headache (III). Experienced stress and stress in relationship with others was also common among the ones with tension-type headache (I, III). This might be related to their difficulty in concentration and memory, as well as fear and worries about what the headache might mean. Arboix et al. (1994) suggest that stress may be the causes, or at least contributory causes, of tension-type headache in CVL.

The participants described themselves as irascible or angry about impediments in daily activities and described their pain as disheartening (I, III). There is much research reporting that particularly depression, minor or severe, but also anxiety, is common in the case of long-term pain (Craig, 1999) and following a stroke (Hafsteinsdóttir & Grypdonck, 1996; Hosking, Marsh & Friedman, 1996). The results of the different investigations in this thesis revealed that mood should be assessed with different methods in order to be as certain as possible of what kind of mood is present. Fernandez & Turk (1995) say that anger is one of the most salient emotional correlates with pain, even though much previous research has focused on depression and anxiety. A recent review suggests that anger should be more systematically assessed in clinical practice since anger may interfere with a therapeutic relationship with health care providers (Greenwood et al., 2003). Greenwood et al. (2003) say that anger in long-term pain can be directed at the sufferers themselves, others, or their life situation, and that anger is an important emotion since it can exacerbate the pain.

Common experiences in all pain groups were that the pain was tiring, troublesome and annoying (I). In the study by Glader et al. (2001), two years after
stroke, most estimated their general health as good, and tiredness was twice as common as depression. The participants in this thesis described their pain as tiring and fatigue was reported by the participants with continuous pain or tension-type headache (I, III). It is difficult, however, to know exactly how much was related to their stroke and/or to their pain. Fatigue is common for long time after a stroke (Glader et al., 2002) and long-term pain is reported to be exhausting (Katz et al., 1996), but a combination of both conditions may increase the problem.

Regarding the participants’ physical disability (II), nearly half were dependent in ADL, and one third of the ones who were independent used assistive devises. These figures are more or less in line with findings in the study by Glader et al. (2001), also performed two years after stroke, and in studies one year after stroke (von Koch et al., 2001; Appelros, Nydevik & Viitanen, 2003). The role the physical impairments had with regard to the participants’ health-related quality of life, according to the results of SF-36 (IV), is not surprising if one consider that all had more or less paralysis and/or spasticity (I) and their dependency on others (II). In addition to the participants’ physical impairments, mainly in motion and/or mobility, their pain was also interfered with their daily life (III), which is in conformity with the results of previous studies on long-term pain (Katz et al., 1996; Robinson, 2003), but there are different opinions as to whether pain is disabling or not (Farrell, Gibson & Helme, 1996). It has been suggested that severity of chronic pain can be defined in terms of the interference of pain with daily life and functioning (Katz et al., 1996; Peolsson, Hydén & Sätterlund Larsson, 1997; Harstall & Ospina, 2003). Among the participants it was proportionally more of the ones with nociceptive/shoulder pain that had difficulty in motion and mobility, and more of them were dependent on assistive devices than the others (II). They were also on average older than the others, therefore the results regarding significantly more difficulty in the role-physical scale of SF-36 in the older group probably mainly refer to the ones with nociceptive/shoulder pain (IV).

Most of the coping strategies used were problem-focused, directed towards their pain and pain-related problems (III), which means that the participants had resources to manage their pain (Lazarus & Folkman, 1984; Lazarus, 1993). Katz et al. (1996) say that how the pain is managed depends on the person’s ability to use appropriate coping
strategies (Katz et al., 1996), and Nordenfelt (2000) maintains that it is important to consider a person’s ability or disability in the light of the person’s goals of the circumstances in which the person acts.

Various attempts at taking medication to avoid and/or relieve the pain were described in all groups, even though they did not experience sufficient pain relief (III). This coping strategy is reported to be common in coping with long-term pain (Aldrich, Eccleston & Crombez, 2000), as is distraction (Breen, 2002; Jensen et al., 2003). Distractions designed to get their mind off the pain in various ways were described or referred to in the different studies (III, IV, V). This strategy has been referred to as a late coping strategy in long-term pain, together with other physical, psychological and social strategies, whilst cure-seeking and medication use are early strategies (Breen, 2002).

Communication, the most common coping strategy used among all (III), may have given the persons some sort of possibility of having verbal control over the pain, as described by Peolsson, Säljö & Sätterlund Larsson (2000). Satisfaction, a positive outcome of their coping, deriving from occasions when receiving considerateness reveals the need of time and continuous follow-up by professionals in community care, as previously emphasized (Pound, Gompertz & Ebrahim, 1998; Kerr & Smith, 2001). The negative outcomes of their coping efforts were mainly perplexity and resignation. The participants described difficulty in verbalizing their pain so others understood their tensions and needs, in the interviews (III, V), which is commonly reported among persons with long-term pain (Katz et al., 1996; Lansbury, 2000). This is often a cause of unrelieved pain (Seers & Friedli, 1996; McCaffery & Ferrell, 1997; Lansbury, 2000) and might be one explanation of the failure experienced in their coping efforts in communicating about their pain. Further, different opinions with regard to pain intensity between the sufferer and the care givers (Weiner, Peterson & Keefe, 1999) and kinds of words used to describe long-term pain and acute pain (Breen, 2002) have been reported, which might be another difficulty in the communication with professionals.

The interviews about HRQoL revealed that meaningful activities and having fun were important (IV). Further, good relationships and support were spoken of as
important in all the qualitative studies (III, IV, V). The importance of the social context for persons with long-term pain and in stroke has been reported in previous studies (Pilkington, 1999; Burton, 2000; Breen, 2002), as well as financial security (King, 1996; Robinson, Murata & Shimoda, 1999; Gerstle, All & Vallace, 2001). The participants had a lower health-related quality of life related to their pain when comparing the results of SF-36 with those of other studies one and six years after stroke (Carod-Artal et al., 2000; Hackett et al., 2000).

Concerning caring, the most manifest experiences in the interviews had to do with experienced uncaring with regard to not only their pain but also to their care in general (V). Pain onset, within one to six months in most of the participants, was after discharge from the hospital, and the results revealed that at the time of investigation most of them were seldom in touch with a doctor or other professionals (I, V). The results revealed that the professionals within primary and community health care seem to lack requisite knowledge, and time when it comes to persons’ problems, especially the pain. The National Board of Health and Welfare in Sweden (2002) says that primary health care and care within the municipality often lack prerequisites and resources needed for this group of patients and their next of kin. Improvement is required since previous studies on stroke emphasize the need of a prolonged follow-up and continuity in the care of stroke patients within community health (Kerr & Smith, 2001). Three months as recommended by Riks-Stroke (2002) is too a short time, since pain onset seems to occur later in many cases. In the early 1990s the National Board of Health and Welfare recommended that patients who do not recover within two to three months should be referred to a pain specialist (National Board of Health and Welfare, 1994), and the importance of early treatment of long-term pain has been emphasized (Bowsher, 1995, 2001).

The findings regarding the participants’ experiences reveal several prerequisites for providing quality in the care (V), which implies professional competence, both being cared for and cared about (Gaut 1983, 1986; Norberg, Engström & Nilsson, 1994). There are several studies reporting the deficiency of knowledge about adequate pain assessment in patients with long-term pain as well as acute pain (Gaston-Johansson, Johansson & Johansson, 1999; Davies & Vicar, 2000; Löfmark,
Gustavsson & Wikblad, 2003), and the commonest barriers to improving pain relief are poor pain assessment and poor evaluation of treatments given. McCaffery & Pasero (1999) state that assessing pain involves a circle of assessment, intervention and reassessment. Pain assessment begins with listening to the person, believing in the persons and taking complaints seriously. There is much research reporting lack of knowledge regarding long-term pain within health care and the need of basic and continuous education. Education has been one of the IASP’s guiding principles. The IASP has recently again emphasized the need of pain education among all professionals, which should not only be included in all curricula but also carried out (Sessle, 2003). This was also emphasized by others (McCaffery & Ferrell, 1997; Twycross, 2000; Sloman et al., 2001).

The need of improved communication emerged in the studies (III, V) and has to do with both caring for and caring about. Without sufficient knowledge about pain, it is difficult to be sensitive to the sufferers’ complaints and take their experiences seriously. Even if the knowledge is there, it has also to do with the attitude among professionals and the way the care is provided. The professionals’ manner was one aspect described by the participants (III). Humour and having fun and the professionals’ spreading of joy were perceived as caring about by the participants. Humour is reported to alleviate stress in human interaction (Olsson et al., 2000) and distractions with emotional content are successful in altering pain perception (Eccleston & Crombez, 1999).

The need of being respected and understood was described, and the results of the interviews revealed the need of integrity, self-esteem, contentment, and being seriously taken (III, IV, V). These are basic human needs and have to do with the moral aspect of caring, but the needs have, however, been emphasized in studies of stroke survivors (Hafsteinsdóttir & Grypdonck, 1997; Hamilton, 2000; Lansbury 2000; Sundin & Jansson, 2003). Continuity, accessibility and participation in the care are the patients’ rights and necessary for providing good care, especially when it comes to persons living with chronic illness, uncertainties and worries. Wyller & Kirkevold (1999) and Hamilton (2000) say that changes in the care of stroke are required regarding attitudes among professionals as well as in their working conditions in order
that they shall be able to fulfil these obligations. The requisite of good working conditions for providing good care has also been emphasized in a recent Swedish study (Lövgren, Rasmussen & Engström, 2001).

**Methodological aspects**

The design with combinations of methods used in this thesis increased the possibility of gaining a perspective taking account of the participants’ point of view and a deeper understanding of their experiences.

The time for investigation, two years after stroke, was chosen so the persons should be able to distinguish the consequences relating to their pain from others. The selection was designed to make it possible to study a group composed entirely of participants with long-term pain following a stroke, and to include them in all studies. The exclusion criteria increased the validity but decreased the generalizability to other stroke survivors, such as those with communicational difficulties. The reason for there being more men than women and for the lower median age of the participants (66 years) than average stroke patients (75 years) was that the patients excluded were older (75 years). There were also more women in the group excluded because of other pain conditions. Women are reported to suffer severe long-term pain more often than men at older ages (Brattberg, Parker & Thorslund., 1997; Bergman, et al., 2001; Bergh, et al., 2003). Women are often in a worse pre-stroke condition when suffering a stroke than the men (Riks-Stroke, 2002) and are reported to have a worse outcome than men in motor, cognitive and ADL function after a stroke (Wyller et al., 1997; Glader et al., 2003).

Regarding the measures, pain intensity in long-term pain requires multiple measures since long-term pain fluctuates and may depend on factors such as the activities performed. Two pain ratings were planned and performed, but because some participants were prescribed pain medication at the clinical examination between the two measures, the results of the second rating were not included. A VAS scale was chosen because it is more sensitive to detecting small changes than the other pain rating scales, even though difficult for some, such as the elderly, to understand (Gagliese & Melzack, 1997; Paul-Dauphin et al., 1999; Campbell, 2003). Thorough
information and the opportunity for the participants to hold the POM-VAS tool in their hands was possible because POM is a larger tool, with a larger marker than the commonly used VAS measures. This facilitated the participants’ taking active part in the POM rating. POM is a valuable tool for pain ratings since it comprises measures of pain both intensity and pain quality. Such instruments are preferable in ratings of both acute and long-term pain since they reflect both sensory and emotional components of the pain (Clark et al., 2002). The body chart included in POM is different from others since the body figure is divided into numbered sections, which makes it easier to distinguish the body parts affected than on other charts. The numbered sections may be confusing but with sufficient communication this was not a problem. The pain analysis most often performed in clinical practice, and in previous research on pain after a stroke, is limited with regard to how the pain influences the sufferers’ lives. A multidimensional instrument (MPI-S) was therefore included (II), and in addition to the quantitative data, the persons’ descriptions in their own worlds were of importance, as shown in the study of pain experience, coping, HRQoL and caring (III, IV, V).

Regarding the assessment of disability, the Self-report impairment screening was a complement to the ADL scale. In the search for an instrument measuring HRQoL, there were only two available in the Swedish language also including the dimension of pain, i.e. SF-36 and the Nottingham Health Profile (NHP). The instrument frequently used in research on stroke was SF-36, which was constructed to be used as a self-report measure including the representation of general health concepts, useful for most groups and not specific to any age or disease. However, there is no single instrument, SF-36 being no exception, for measuring HRQoL for all purposes (Larsson, 1997; O’Mahony et al., 1998; Weimar et al., 2002b). The HAD Scale was chosen as a complement since mood disorders in both stroke and long-term pain are commonly reported and to influence HRQoL. The results in respect of HRQoL and mood disorders (IV) might have been influenced because some of the participants were prescribed medication at the clinical examination and obtained pain relief, and that data was collected after this. From the ethical point of view, decreasing of suffering has always to be given the priority, including research.
Psychometric characteristics refer to validity and reliability evidence in quantitative studies. Validity refers to the content and whether the measure assesses the domain of interest, and reliability refers to the consistency of the measure. Internal validity has to with to what extent an intervention can be considered to account for the results rather than external influences, and external validity has to do with to what extent the results can be generalized (Kazdin, 2003). Even though this thesis does not comprise interventions, the aspects of internal and external validity have been considered.

Internal validity was considered in the studies (I, II, IV), since only the persons with long-term pain after stroke were included and the same participants in all studies. The total data collection was performed within a certain time period and in steps, in an attempt to avoid bias by other incidents in the participants’ lives and the influence of the items in the instruments. The three investigators involved in the first study were responsible for independent areas of the data collection at different times, which should not, be seen as a threat to the internal validity. There was a difference between the demographic variables regarding gender and household status that might have been a threat to the internal validity. Regarding age, there were the same proportions in the younger and the older groups of participants. Another threat might have been the “Hawthorne effect” in some since the participants were informed about the medical examination in the introductory letter. Another aspect of it is that the participants said nobody had shown interest or asked them about their pain before, which motivated them to participate in all data collection (Kazdin, 2003).

The small number of participants as well as the small group sizes was a limitation of the quantitative studies (I, II, IV) which was a threat to the external validity (Kazdin, 2003). Therefore a larger number of participants and/or a comparison group would in this respect have been preferable. The problem of small groups when it comes to getting significant results has also been reported in a previous study on pain after stroke (Lampl, Yazdi & Röper, 2002).

The validity and reliability of the instruments was considered before the data collection, as described in the methods section. All instruments, except for the Self-reported impairment questionnaire, had undergone psychometric testing with
satisfactory results (Streiner & Norman, 1995). The instructions regarding the
instruments were given by the same investigator. It was emphasized that the
questionnaires should be answered by the participants, which was reported to have
been carried out by all, except two because of hemiplegia.

The interpretation of the qualitative data with an inductive approach made it
possible to gain an understanding of the meaning of the pain for the participants, and
as reported by Hamilton (2000) and Patton (2002), one can learn a lot even about
things one cannot predict. Trustworthiness including credibility, transferability,
dependability and confirmability, the criteria in qualitative research, was considered.
Credibility refers to confidence in the truth of the data, how the investigation is carried
out through data collection and analysis, and the credibility of the researcher (Lincoln
& Guba, 1985). Sufficient time was given during the interviews, as well as time
afterwards, so any obscurities could be sorted out. The sensation and expression of
pain is completely subjective and there are no entire objective measures (McCaffery &
Pasero, 1999). Therefore the attitude is of importance when investigating pain and
communicating about it (Jacobson & Mariano, 2001), which implies building trust,
which was considered in the communication with the participants. Open-ended
questions were asked in order for the participants to be able to be reflective and speak
freely at length. Most of the data collections were in the participants’ home
environment because it was most convenient for them, and because the natural context
facilitated the data collection. Their next of kin were not present during the interviews.
The credibility of the investigator derived from the prolonged commitment during the
data collection, knowledge of and familiarity with the participants, acquired through
“face to face” contact (Lincoln & Guba, 1985). In order to obtain neutrality, the co-
authors took an active part, read the data and checked all the steps of analysis which
should guarantee dependability. Another aspect was that an interview guide was used
in order to state the questions in the same way, furthermore all interviews were tape-
recorded and transcribed verbatim. Since there are no qualitative studies entirely on
persons suffering from pain after a stroke, transferability or applicability was difficult
to obtain (Lincoln & Guba, 1985; Patton, 2002).
In one study (V) the most information-rich narrative data was chosen for further analysis after the reading and labelling of all the data. Patton (2002) says that selecting the most information-rich data, a purposeful sampling, derives from the emphasis on in-depth understanding which increases credibility. Information-rich cases are those from which one can learn most about issues of central importance to the purpose of the inquiry. In order to increase the transferability to all participants, the themes and categories obtained from the most information-rich data were scrutinized for their content and relevance to the context of all data (Lincoln & Guba, 1985; Patton, 2002).

**IMPLICATIONS**

The results reveal the need of a more regular follow-up, in order to prevent suffering and maintain or increase health-related quality of life after a stroke, since pain occurred after the discharge from the hospital and the time of rehabilitation in most participants. The three months follow-up recommended by Riks-Stroke (2002) is too a short time in this respect. All persons with long-term pain after a stroke are in need of greater attention from professional, as previously reported (Weimar et al., 2002a; Jensen & Baron, 2003; Ratnasabapathy et al., 2003).

Communication with and paying attentions to persons suffering from long-term pain and other care givers is essential, as shown in this thesis. Nearly all participants received help from next of kin regularly and the latter also need attention and guidance in order to be able to give practical and emotional support. Even though team-work often is required in the care of persons suffering from stroke, it is important that one of the professionals assume the main co-ordinating responsibility, and which one depends on the situation. Most often it is the nurses who have the regular contact with the carers and the care receiver in community health.

Lack of knowledge and understanding of the participants’ pain was manifest in all the results. An adequate and documented pain assessment, including a medical pain diagnosis, should be established as soon as a person complains about long-term pain. Therefore improved knowledge among all professionals about long-term pain assessment and pain management is required. Regular update is necessary because of
the rapid development of new knowledge. According to a recent report from the IASP, the time devoted to pain in the curricula on all levels of medical, paramedical and nursing education is too limited and needs to be extended and implemented.

Long-term pain is reported to be one of the most difficult areas within medicine and care and therefore, even if the pain cannot always be completely relieved by medication, it is important to make use of the other ways of bringing comfort that are applicable if the person’s needs, goals and interests are known. Getting to know a person takes time and establishing relationship is a process which requires continuity. There are many ways of support and enhancing distraction, which should be individually tailored, such as music and relaxation, humorous events or hobbies. One important part of the therapeutic interventions that has emerged in this thesis is the need of care provider’s attention, concern and careful listening. Listening and responding to persons requires competence including empathy in order to understand their problem.

Patient education and information about treatment options in respect of long-term pain are required in the case of both the sufferer and their next of kin. It is also important to assess the patient’s understanding of information given and willingness to learn. Long-term pain implies balancing physical and daily situational circumstances, and thereby requires recurrent information, and follow-up of treatments and information given.

There is a need of further studies about how long-term pain after a stroke affects the specific daily activities of persons with physical impairments and also a need of instrument development regarding this area. More qualitative studies are needed about coping and how specific pain-related problems are managed. Further, longitudinal studies on coping and health-related quality of life are needed, if possible with a comparison group. Another area of importance is the need of studies of the next of kin’s experiences of living with a person suffering from long-term pain after a stroke.
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