Efficacy of Individual Pain Treatment on Quality of Life of Patients with Dementia in Nursing Homes.

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List of abbreviation

AD   Alzheimer`s Disease

BPD   Blood Pressure (Diastolic)

ICD   International Classification of Diagnosis

MOBID-2   Mobilization-Observation-Behavior-Intensity-Dementia-2 Pain Scale

NH   Nursing Home

QOL   Quality of Life

SA   Social Activity

BPS   Blood Pressure (Systolic)

SPSS   Statistical Package for the Social Sciences

WHO   World Health Organization

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Abstract

People with dementia, particularly those who reside in nursing homes, are at high risk of under-recognition and under-treatment of pain. Under-treatment of pain is associated with gait disturbances, falls, malnutrition, increased morbidity, increased mortality, sleep disturbances, decreased socialization, depression, impaired immune functions, and agitated behavior, that pose threats to the quality of life of residents with dementia in nursing homes. This study focuses on the impact of individual pain treatment on the quality of life of nursing home residents with dementia, in west-coast of Norway. About 66 residents were recruited from five nursing homes and they were subjected to randomization. After randomization, residents were divided into two groups; the intervention group, where residents were given individual pain treatment for the period of eight weeks, and control group, where residents were not treated for pain. At the end of the next four weeks, after the intervention period, some of the measures were repeated in both the groups, as a follow up study. The variables measured to study the quality of life were, systolic blood pressure, diastolic blood pressure, pulse rate, participation in social activities, skin problems and depression. To analyze the data, descriptive and correlation analysis were used by using SPSS-18 for Windows. The major findings from stepwise-regression analysis in experimental group indicated that pulse rate and depression were the ultimate predictors of quality of life of nursing home residents with dementia.

This thesis is written as a part of the Master Study in Health and Social Sciences, with major focus on empowerment, at University of Stavanger, Norway, 2011. This thesis is divided into two parts; the first part is the main summary of the study, supported by theories, and the second part is an article which is planned to be sent for publication in Scandinavian Journal of Caring Sciences.

1.0 Introduction

1.1 Objective of the study

The prevalence of persistently painful conditions among older adults is particularly noteworthy in light of their association with functional impairment, sleep disturbances, depression and anxiety and decreased socialization (AGS Panel, 2002). The prevalence of dementia is known to have a linear relationship with age. Thus, a significant number of ageing population also suffers from dementia. The prevalence of degenerative dementia and those associated with cardiovascular disease is increasing due to the ageing of the population. The World Health Organization has calculated that there would be 29 million people worldwide affected by dementia by the year 2020 and that two-thirds of these cases would be due to Alzheimer`s disease (AD) (Chapman et al., 2006). In Norway, the number of people with dementia is approximately 70,000, and the number is expected to double within the next 30 years (Engedal & Haugen, 1993).

Older people, especially with dementia, are at risk of suffering from falls and fall injuries, skin problems like psoriasis, fungal infections and eczema, due to difficulties in maintaining personal hygiene, diabetic foot, pressure sores, arterial and venous wounds, and undiagnosed fractures, which contribute to their chronic pain. The association between pain and depression in older adults has been demonstrated consistently (Moss et al., 1991; Parmelee et al., 1991 & Cohen-Mansfield & Marx, 1993). Clinical characteristics such as functional disability, comorbidity, cognitive limitation and pain are strong correlates of depression in various elderly populations. This may influence the patient`s perception of helplessness and ability to maintain important social roles, which, in turn, may result in elevated level of depression and poor adjustment.

Even when older people report pain, most studies have identified an alarming trend toward leaving pain untreated in as many as 85% of old people with identified pain and/or pain causing diagnoses (Ferrell et al., 1990). Failing to adequately treat pain can lead to host of problems and can make the person with dementia susceptible to worsened health as well as poor quality of life (QOL).

Keeping the above points in mind, the present study was planned with the following objectives:

To explore the efficacy of individual pain treatment in dementia patients residing at nursing homes (NHs) on:

- Patients` quality of life

- Depression level

- Socialization with other Nursing Home (NH) patients and their participation in NH`s social activities

- Skin problems caused by different kinds of infections/wounds

- Physiological measurements like blood pressure and pulse rate

1.2 The relevance of the patient-perspective

In this study, emphasis is on the patient`s subjective experience of their QOL as NH resident – thus, it has a patient perspective.

Subjective evaluation of QOL by people with dementia may be influenced by their cognitive limitations and may reflect reduced insight. However, in understanding the perceptions and experience of life with dementia, the patient-perspective may be regarded as more valid than any set of objective criteria.

1.3 Theoretical Framework

Lazarus and Folkman`s (1984) Transactional Model of Stress and Coping provided the theoretical framework for the present study. It was Lazarus and his coworkers who led to the significance of cognitive appraisal and thus it got the importance in stress research. In the present study, NH residents are suffering from chronic pain, are constantly under stress, which is a negative emotional experience accompanied by predictable biochemical, physiological, cognitive and behavioral changes, that are directed either towards altering the stressful event or accommodating to its effects. Stress is defined here as a strain or an external demand which is higher than person`s coping resources

and that threatens individual`s well-being. Physical, physiological and psychosocial variables in the present study can be considered as mediating variables in the process of coping in nursing home residents with dementia and pain.

Lazarus and Folkman proposed one of the most comprehensive theories of stress and coping in the psychological literature. However, their model has reviewed little empirical attention in chronically ill populations in NH settings. The present study sought to address the basic hypothesis of Lazarus and Folkman`s Transactional Model of Stress and Coping, which is considered to be the most suitable theory, with a sample of persons with dementia, suffering from chronic pain, living in nursing homes.

Stress is a consequence of person`s appraisal process; the assessment of whether personal resources are sufficient to meet the demands of the environment. Stress, then is determined by person-environment fit (Lazarus and Folkman, 1984; Lazarus and Launier, 1978). The theoretical model is built on the assumption that stress is a person-environment interaction, one that is dependent on the subjective cognitive judgment that arises from the interplay between the person and the environment (Zokowski et al, 2001). No event or situation in itself is inherently stressful; instead the stressor is defined by the subjective judgment of the situation that is appraised as threatening, harmful or taxing of available resources (Lazarus and Folkman, 1984).

With this background, Lazarus` model can be said as a transactional model, because according to this model, stress is a transaction between a person and the environment. When the individual perceives that his or her resources will probably not suffice to meet an environmental stressor, he or she may experience a great deal of stress. Stress, then results from the process of appraising events (as a harmful, threatening and challenging), of assessing potential responses, and of responding to these events. Stressors are external events that are potentially threatening to the organism. In this model, we can consider that for individuals with dementia, pain can be interpreted as direct "stress", which may, in turn, affect their physical, physiological and psychosocial symptoms and/or their rates of illness. Since older people have many other complications, such as urine infection and skin infections due to various kinds of wounds and in addition, loss of memory can be experienced as a tremendous stress situation.

According to Lazarus, the stress process is mediated by cognitive appraisal and therefore coping is the main construct in his model (Lazarus, 1966). Appraisal and coping processes are closely interrelated. Cognitive appraisal is an evaluating process that determines why and to what extent a particular transaction between the person and environment is stressful or else to what extent it is important to his or her general well-being (Lazarus & Folkman, 1984).

There are two types of cognitive appraisal, called as primary and secondary appraisal. When an individual confronts a new or challenging environment, he or she engages in a process of primary appraisal to determine the meaning of the events. Primary appraisal of a significant stressors, like a chronic pain and illness, involves the patient`s evaluations of the meaning of the stressor and a decision whether the stressor is irrelevant, relevant or stressful. Primary appraisal of events as threats have important effect on physiological responses to stress, for example, blood pressure is higher when threat is higher (Maier et al., 2003). The secondary appraisal is the assessment of one`s coping abilities and resources and whether they will be sufficient to meet the harm, threat and challenge of the event. Such resources can be of internal or external type. Ultimately the subjective experience of stress is a balance between primary and secondary appraisal. Coping is the process through which the individual manages the demands (external or internal) of the person-environment relationship and the ensuing emotions generated from the situation. In that way, secondary appraisal influences the primary appraisal by either decreasing or increasing the experience of stress, which, in turn, may influence the coping strategies adopted (Lazarus & Folkman, 1984; Lazarus & Launier, 1978).

The impact of stress caused by chronic illness and pain experienced by nursing home residents with dementia may depend upon the interplay between stress resistance resources (participation in NH`s social activities and social support from nursing home staff, other residents and families) and the individuals coping efforts (Kessler et al., 1985). Effectiveness in coping may reduce the deleterious impact of stress and improve the individual`s well-being, whereas maladaptive coping strategies would result in depression or negative health behaviors that amplify disease progression. Painful chronic wounds would lead to increased behavioral problems, thereby influencing negatively on their social and daily living activities. This will further increase the stress situation,

thereby affecting their quality of life. Thus, the people with dementia, suffering from chronic pain, enter into a complex dynamic process, thereby interfering the appraisal of different situations in nursing homes.

The following model (figure 1) will explain the relationship between the factors included in this study, as seen from Lazarus and Folkman`s cognitive stress-coping theory.

Figure 1: The model illustrates a continuous process where there is a reciprocal influence of environment and a person. The arrows in opposite directions show that a person`s experience with stress management influences the further process.

| Person in Context | Internal Factors:

• Depression
• BP/Pulse
• Skin Problems (Wounds)

External Factors:

• Social Activities
• Social Support from NH staff and other residents | Appraisal/experience of the situation

Harmless

Challenging

Threatening

Choice

of

coping

strategy | Quality

Of

Life |

PAIN

Nursing Home Environment
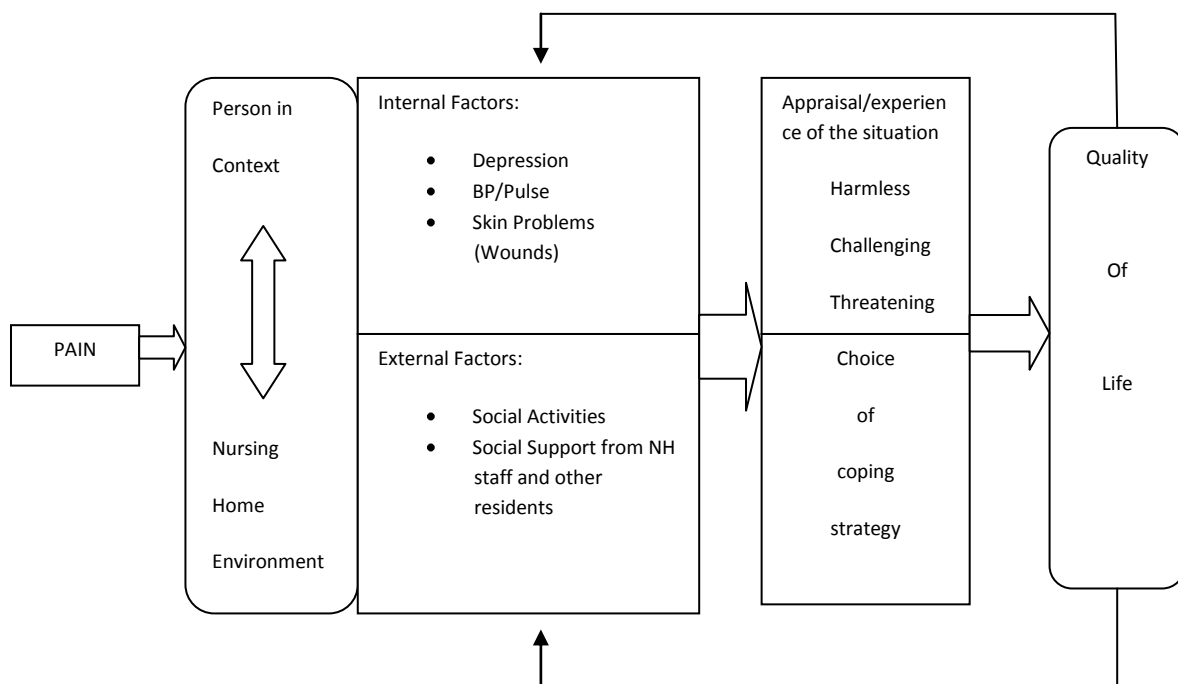
The Choice of coping strategy was not done in the present study, but it is depicted in the figure to maintain continuity in the model.

The main focus of the study is to explore the impact of individual pain management and treatment in dementia patients residing in NHs and the effects of chronic pain on their physical, physiological and psychosocial aspects, ultimately affecting their QOL. This chapter will address the aspects of these variables specially related to NH residents with dementia.

1.4 Dementia and Pain

Dementia such as Alzheimer`s disease type dementia and vascular dementia in elderly persons encompasses a group of conditions characterized by gradual decline in cognitive abilities that is accompanied by progressive decline in functioning in many aspects of living, including communication, activities of daily living (ADL), work, leisure and social activities (Cohen-Mansfield et al., 1996). Since older persons with dementia have less communicative skills and suffer from pain and exhibit more agitation, pain may be contributing factor in these patients. Few studies have explored such a relationship, but there is some preliminary support for this hypothesis (Barton, 2005; Zannini, 2004). This is of key importance since a relationship between pain and agitation will have therapeutic implications, implying that pain medication could improve agitation in dementia.

In Nursing Homes, 80% of the patients have dementia, and a considerable proportion of patients with dementia exhibit behavioral and psychiatric disturbances (BPSD) (Cipher et al, 2006; Selbaek et al., 2007). Common BPSD symptoms in dementia include depression, apathy, withdrawal, irritability, agitation, aggression, wandering, change in sleep pattern, socially disruptive behavior and sundowning syndrome (Cohen-Mansfield & Libin, 2004; 2005). Such disruptive behaviors often indicate discomfort in the person with dementia and are the major sources of stress. The physiological, psychological and environmental changes that accompany ageing and restrict homeostasis may further exacerbate the consequences of persistent pain (Karp et al., 2008). Homeostasis, that is maintaining stability through change, is the response of the body to stress by activation of physiological reserves (McEwen, 2003). These reserves include cognitive and emotional resilience to stress and activation of the neuroendocrine system, the autonomic nervous system and the immune system. In contrast to the homeostasis, homeostenosis is the construction of an ageing organism`s ability to effectively respond to stress because of

diminished biological, psychological, and social reserves (Resnick, 1994; Troncale, 1996). When the inherent reserve capacity is exceeded, this may result in disability or death.

Pain has been highlighted as a significant problem for many old people as they are more susceptible to the experience of pain (Wallace, 1994). This is partly due to the high prevalence of musculoskeletal disorders, phantom pain, pressure ulcers, cancer and other medical conditions in this age group (Ferrell, 1991). In most NH residents, due to incurable chronic diseases, complaints of pain range in prevalence from 45% to 83% (Ferrell, 1995; Ferrell et al., 1995; Parmelee, 1994, 1996; Parmelee et al., 1993). Despite the NH residents exhibiting high prevalence of pain, and functional disability, which is potentially made worse by pain, pain remains unidentified and untreated by NH staff particularly in patients with dementia (Won et al., 1999; Barnabei et al., 1998).

There are different definitions of pain, but in the present context, pain defined by Hicks (2000), is most suitable. As per his definition, pain is a highly individualized, unpleasant experience involving all aspects of the person, amenable to intervention, yet when left unattended, results in the decreased overall quality of life.

1.5 Depression

The most important impetus for evaluating QOL stems from the psychological distress that chronically ill patients often experience. The chronically ill are more likely to suffer from depression, anxiety and distress (De Graaf & Bijl, 2002; Mittermaiier et al., 2004). Depression, psychological distress and neuroticism contribute to substantially increased risks for mortality from chronic conditions (Christensen et al., 2002). Stress exacerbates the symptoms and course of many chronic illnesses and since depression is a common consequence of stress, reducing stress levels and managing those stressors that cannot be eliminated are paramount for the management of chronic illness. However, inconsistent to the present study, other studies have shown that chronic illness does not always lead to depression. The findings of Murberg et al (1998) has indicated that depression among heart failure patients is not primarily related to severity of chronic heart failure illness, nor to the somatic symptoms of dyspnea but rather to the perception of impairment in activities of daily living.

Depression increases with the severity of illness (Moody et al., 1999), which in turn, increases pain and disability. These problems are aggravated in those who are experiencing other negative life events and lack of social support (Thompson et al., 1989).

Medically unexplained symptoms of pain and bodily dysfunction are the single most prevalent class of symptoms in primary care. Patients with medically unexplained physical symptoms have been shown repeatedly to have increased rates of depression and anxiety (Bass et al., 2001; Katon et al., 2001; Von Korff and Simon, 1996). The association might signify a reactive increase of depression and anxiety in patients suffering from chronically bodily symptoms (Nielson & Merskey, 2001). Alternatively, bodily and psychological symptoms may be related but have different expressions of common distress (Sharpe & Carson, 2001). Finally, these bodily symptoms or the heightened awareness for them could represent a primary psychological phenomenon, a consequence of depression and anxiety (Gillespie et al., 1999; Goldberg, 1996).

In recent years, a variety of effective cognitive and behavioral interventions have been developed to deal with the depression that so frequently accompanies illness (Center for the Advancement of Health, 2000f). Treatment of depression may not only alleviate psychological distress but also improve functioning by reducing symptoms associated with the illness.

1.6 Social activities

The purpose of social activities (SA) in NHs is to enable residents to react and interact with their environment, to help them to find new and satisfying social relationships and to be able to be self-directing and spontaneous. For elderly people with dementia, participating in activities and taking part in social events become more difficult due to deterioration in physical and mental health, mobility limitation and lack of communication, thus forcing elderly people into isolation. The isolation experienced by elderly people can lead to lowered self-esteem and depression which can cause more serious health problems. Today`s elderly care facilities, such as NHs take the psychological implications of isolation into account and attempt to create an active

environment for elderly residents. Recognizing the generalized perception of substandard QOL in NHs, the Institute of Medicine recommended in 1985 that residents should be cared for in such an environment as will promote maintenance or enhancement of their QOL (Uman et al., 2000).

Research studies have demonstrated that older individuals are benefitted with therapeutic recreation services. Those, who received exercise programs, experienced significantly increased cardiovascular fitness, decreased blood pressure and increased flexibility, strength and ambulatory skills (Buettner & Ferrario, 1998). Appropriately targeted exercise programs of sufficient intensity increased and improved muscle strength, balance and cardiovascular fitness in older people (Buchner et al., 1992; Fiatarone et al., 1990). Exercise to improve strength and balance have therefore been central to most fall prevention programs. A meta-analysis (Heyn et al., 2004) identified 30 randomized controlled trials of exercise interventions with cognitively impaired older adults and showed that exercise training had a significant positive effect on measures of health-related physical fitness, as well as behavioral, functional and cognitive functions. Teri and coworkers (2003) have shown in their study that exercise programs improve physical health and depression in individuals with dementia.

Research with NH residents has shown that the use of purposeful activity reduces agitation, decreases pharmacological use, and enhances QOL for this population (Kolanowski & Buettner, 2008; Brooker & Woolley, 2007; Fossey et al., 2006).

1.7 Skin problems

Wounds are the significant problem at the end of life of NH residents. Unsurprisingly, the majority of wounds are pressure ulcers, but ischemic wounds, diabetic foot ulcers, venous stasis ulcers are also significant. Pressure ulcer risk is increased with poor nutrition, immobility, loss of cognitive function, and incontinence (Lekan & Colling, 2003), all of which are seen in the end-of-life population. Fall is also a major health problem among NH population. Abnormalities of balance and gait, psychoactive drug use and dementia have been shown to contribute to fall risk (Sterke et al., 2008), which contributes to fall-related injuries and post fall anxiety (Sattin et al., 1999; Tinetti et al.,

1995; Nevitt et al., 1991). In addition, due to dementia and behavioral problems, it is difficult to prevent and treat their wounds.

Venous leg ulcers are a type of chronic wounds affecting up to 1% of adults in developed countries at some point during their life (O`Meara et al., 2008). Many of these wounds become non-healing to the extent that the patient may live with them all of his life, or even die because of them. Some wounds result in chronic discharging wounds that cause pain and impact upon QOL and social function. Persons with dementia may be more susceptible to skin problems if their hygiene is difficult to maintain. Not enough attention is paid to the underlying contributing problems specific to the elderly patients. These factors are physiologic (aging skin, immune state and atherosclerosis) and pathological situation (diabetic diseases, ischemia of leg). Therefore, the geriatric approach to a non-healing wound is comprehensive and multidisciplinary, including patient`s co-morbidities, activity in daily living, nutritional status, social support, ethical beliefs and QOL and not only the wound itself (Jaul, 2009).

In recent years, there has been growing evidence that the experience of living with a chronic wound has a significant impact on patient's QOL (Frank et al., 1994; Price & Harding, 1996). A constant finding, particularly in the qualitative work, pain is a symptom patients find particularly distressing (Charles, 1995; Ebbeskog & Ekman, 2001; Rich & McLachlan, 2003). In a multinational survey, practitioners consistently rated dressing removal as the time of greatest pain (Moffatt et al., 2002). Health professionals are now starting to recognize the importance of addressing the issue of wound pain, as evidenced by the recent European Wound management Association Position Document (European Wound Management Association, 2002). The ultimate goal therefore has been altered from healing of wounds to symptom control, prevention of complications and to contribute to the patient`s overall well-being.

1.8 Blood pressure and pulse rate

Blood pressure (BP) is one of the most widely recorded physiological functions of the body. It is one of the body`s vital signs that indicates present cardiovascular function as well as risk for future cardiovascular morbidity and mortality (Kannel et al., 1997).

Acute pain increases BP by increasing sympathetic activity but the role of chronic pain on BP is less well understood. It has been reported in a number of studies that there may be a deficiency of endogenous opioids in patients with chronic pain. Blood-pressure-pain relationship was studied by Bruehl et al (1998) and they reported that those who reported more frequent and intense pain had higher BP. Maixner et al (1997) found no relationship between BP and sensitivity to acute pain in patients with temporomandibular joint disorder. Thus, the normal pain-blood pressure relationship is absent or reversed in these patients. Bruehl et al (1998) suggested that persistent pain leads to generalized arousal and elevation of BP. This, in turn, leads to baroreceptor stimulation, which acutely lowers pain sensitivity, partly through release of endogenous opioids. However, over the long term progressive opioid dysfunction occurs, resulting in a decrease of endogenous opioids and their painkilling effects and hence a vicious cycle whereby further pain leads to further arousal and decreased pain tolerance, supported by Nordin & Fagius (1995).

Acute pain increases pulse rate via autonomic nervous system stimulation and catecholamine release in both animals and human populations (Hampf, 1990; Lewis et al., 1994). Other factors that affect the pulse rate are age, body build and size, BP, exercise and muscular activity, food intake, elevated body temperature and emotional status; medications, illness, and cardiovascular conditioning that affect the pulse rate (Rosenzweig, 2000; Ducharme, 2000). Increased pulse rate may be useful in clinical practice to indicate the presence of pain in patients with cognitive impairment, who are unable to report their pain (Coffman et al., 1997; Hamill-Ruth & Marohn, 1999; Oberlander et al., 1999; Porter et al., 1999).

 1.9 Quality of Life

The term Quality of Life is used to evaluate the general well-being of individuals. The term is used in a wide range of contexts, including the fields of international development, healthcare and politics. QOL should not be confused with the concept of standard of living, which is based primarily on income. Instead, standard indicators of the QOL include not only wealth and employment, but also the built environment, physical and mental health, education, recreation and leisure time and social belonging.

Although the broad impacts of AD are increasingly recognized, little work has focused on the QOL experienced by AD patients.

QOL is commonly defined as the individual`s perceptions of his or her position in life, in the context of the culture and value systems in which he or she lives and in relation to his or her goals, expectations, standards and concerns (WHO-QOL, 1995) or in more general and operational terms, as the individual`s perceptions of his or her functioning as well-being in different domains of life (Fayers & Machin, 2000).

These definitions highlight the difference between QOL and the individual`s functional status which measures how the pain objectively affects the patient`s physical and emotional functioning and capabilities.

The World Health Organization (WHO) definition of QOL assumes that individuals have the intellectual capacity to make complex subjective judgments about their lives. Many questions have been raised about the ability of persons with dementia to make such judgments and about the point at which they become unable to do so (Rabins et al., 1999). Although studies in dementia have used patient`s rating, proxy rating or both, patient`s subjective rating may be the gold standard for measuring QOL in dementia (Brod et al., 1999; Logsdon et al., 2002), thereby empowering them to judge their own QOL.

The duration of pain is an important aspect of pain that may be expected to impact QOL. Again, pain intensity affects the QOL as expected; the more intense the evaluated pain, the greater is the impact of pain on QOL (Skevington, 1998). The extent of pain is another aspect of pain which affects QOL. Widespread pain impairs QOL more than the regional pain does (Croft et al., 1993). There is an evidence that the impact of pain on QOL depends, to some extent, on the underlying diseases (Haythornthwaite et al., 1998).

Treatment designed to reduce pain may be expected to affect QOL favorably. There is plenty of research work that shows that QOL is associated positively with more effective treatment of pain (Zhao et al., 1999; Mannix et al., 1999; Aparasu et al., 1999).

QOL is indicated not only by a relatively good medical and functional health status, but also and perhaps even more so by psychological and social well-being, as it is about being

well or the subjective experience of life. Psychological and social well-being are important domains in most approaches, the former often considered as the central outcome (Gerritsen et al., 2004). Sometimes, however, only negative scales such as depression are used in measurement of QOL. Thorgrimsen et al (2003) found that depression in people with dementia was strongly associated with self-rated QOL.

1.10 The interplay between physical, physiological and psychosocial variables and coping in NH residents with dementia, suffering from chronic pain

The individual`s ability of being flexible in the experience of stressful events involves a dynamic interplay between physical, physiological and psychosocial variables and coping efforts.

"Coping is a constantly changing cognitive and behavioral effort to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141).

Coping consists of efforts, both action oriented and intrapsychic, to manage environmental and internal demands and conflict among them. The relationship between coping and stressful event is a dynamic process. Coping is a series of transactions between a person who has a set of resources, values and commitments and a particular environment with its own resources, demands and constraints (Lazarus & Launier, 1978). Coping is considered as a set of strategies that are available to be implemented to match specific situation.

Previous research suggests that when people are confronted with major stressful events, their coping styles play a significant role in the subsequent perceived physical and psychological well-being (Endler & Parker, 1990). According to stress-coping models, coping has two functions: 1. The management of the problem (problem-focused coping), and 2. The regulation of emotion (emotion-focused coping). Problem-focused coping styles involves efforts aimed to deal directly with the stressful encounter, whereas emotion-focused coping styles involves efforts aimed to deal with emotion aroused by the stressor (Carver et al., 1989). Usually, emotion-focused strategies are associated with poorer adjustment and increased depression (Aldwin & Revenson, 1987), whereas

problem-focused strategies are reported consistently to be associated with better psychological adjustment and decreased depression (Folkman et al., 1986).

NH residents with dementia suffering from either age-or skin related chronic pain, are exposed to lot of stress. Behavior and communication problems interfere in appraisal of the situation. Acute and chronic pain affects the physiological variables like BP and pulse rate, and psychosocial variables as well, such as depression. Residents with pain isolate themselves, thereby refusing to participate in NH`s social activities. Supportive network that increases the patient`s self-esteem and perceptions of physical and functional capability may, in turn, influence the coping strategies used. Many older adults have excellent coping skills and live with persistent pain that is not disabling, whereas individuals, those who suffer from comorbid dementia and/or depression, however, show behavioral changes including decreased ability to cope with pain. They may use the inadequate coping strategies and to maladjustment (Waltz, 1986), which in turn reduces their QOL as in control group (see figure 2).

Figure 2: shows effect of chronic pain on QOL as in control group.
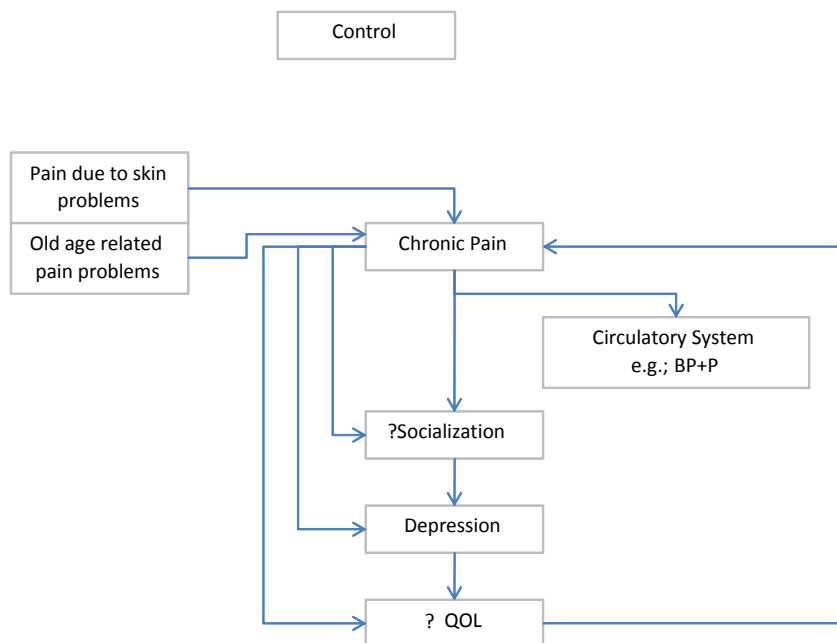
Figure 3 : shows effect of pain treatment on QOL as in experimental group.

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                          ┌──────────────┐
                          │ Experimental │
                          └──────────────┘


┌──────────────┐                          ┌──────────────┐
│ Pain due to  │─────────┐                │ Pain Treatment│
│ skin problems│         ↓                └──────────────┘
└──────────────┘    ┌──────────────┐            │
┌──────────────┐    │ Chronic Pain │←───────────┘
│ Old age      │───→│              │
│ related pain │    └──────────────┘
│ problems     │         │     └──────────────┐
└──────────────┘         ↓                    ↓
                    ┌──────────────┐    ┌──────────────────┐
                    │ ↓Chronic Pain│←───│ Circulatory System│
                    └──────────────┘    │ e.g.; BP+P       │
                                        └──────────────────┘

                    ┌──────────────┐
                    │ ↑Socialization│
                    └──────────────┘
                           │
                           ↓
                    ┌──────────────┐
                    │ ↓Depression  │
                    └──────────────┘
                           │
                           ↓
                    ┌──────────────┐         ↑
                    │ ↑QOL         │
                    └──────────────┘
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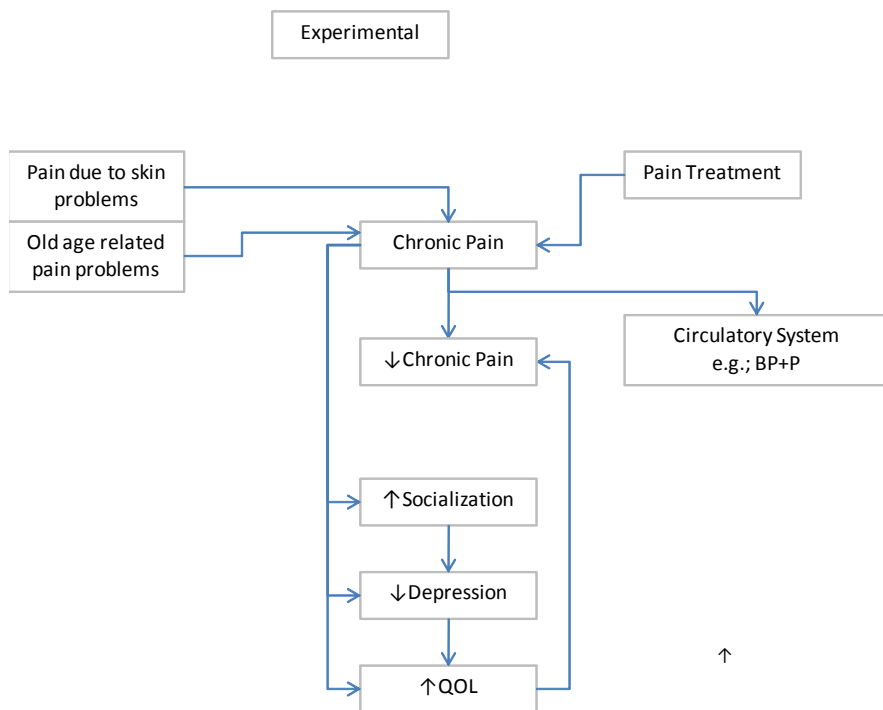
On the other hand, pain assessment, management and treatment of these patients with dementia by the NH staff and clinicians, who are unable to self-report about their pain; ultimately make them more socialized in NH environment. Lazarus and Folkman (1984) consider social support to be a resource that influences the way one copes. Antoni (2002) suggested that social support can be viewed as a coping resource to the extent that it channels, facilitates or perpetuates the use of coping strategies with stress-buffering qualities.

Schmitz and Crystal (2000) sought to bring clarity to the association between social support and coping. They examined the interrelationship among social support, coping style and psychological distress. Their research suggests that individual's perceptions of social support form the foundation from which coping choices are made.

Pain treatment can be compared with problem-focused strategy, which people with dementia are unable to do by themselves. This, in turn, will help them with better psychological adjustment and decreased depression and ultimately they will experience better QOL as hypothesized in experimental group (see figure 3).

1.11 Hypotheses

On the basis of the above model, we hypothesize that

1. there is a significant correlation between pain treatment and increased quality of life in intervention group in contrast to control group.

2. there is a significant correlation between pain treatment and reduced depression in intervention group in contrast to control group.

3. there is a significant correlation between pain treatment and reduced skin infections and different types of wounds in intervention group in contrast to control group.

4. there is a significant correlation between pain treatment and increased participation in nursing home`s social activities in intervention group in contrast to control group.

5. there is a correlation between pain treatment and physiological measures such as blood pressure and pulse rate in intervention group in contrast to control group.

2.0 Methods

The present study is a part of a larger cluster randomized trial (Husebo et al., 2010)

This study is approved by REK-Vest and the Data Inspectorate. The conduct of the study was in accordance with the medical research Council Guidelines for Clinical Practice in Clinical trial (1998).

Study Population

About 134 NH patients were screened from about 5 NHs in west coast of Norway to find patients with dementia. Patients were included in the study after they met all the inclusion criteria and none of the exclusion criteria.

Inclusion Criteria

- Age 60 and above

- Residing in the NH for at least for 3 months

- Dementia according to Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association 1994)

- Informed consent from all participants and/or their relatives.

Exclusion Criteria

- NH clinicians consider that the patients suffer from any physical conditions which would increase suffering by participating in the study

- Advanced severe medical diseases with expected survival less than 6 months

- Severe mental disorders such as psychosis or severe aggression

- Schizophrenia, schizoaffective disorders and bipolar disorders

- Uncontrolled epilepsy

- Severe liver and renal failure

- Bed-ridden

- Injury, anemia, comatose state, or enrollment in another project

- Known allergy to Paracetamol, Norspan plaster or Lyrica

- Current high dose of analgesics

- Use of as-need analgesics (other than Paracetamol was not allowed in participants as they were monitored during the study)

Sample

After screening, about 66 patients with dementia were selected for the study. After obtaining the informed consent from all the participants and/or their relatives, patients were included in the study and they were subjected to randomization. Patients were randomized into two groups:

1. Intervention Group: This group consisted of 34 patients who were given individual pain treatment based on pain assessment by Mobilization-Observation-Behavior-Intensity-Dementia (MOBID-2) Pain Scale (Husebø et al., 2008), for the period of 8 weeks.

2. Control Group: This group consisted of 32 patients who were not treated for pain, but medical management for physical and psychiatric disease was routinely done without active management of pain for the period of 8 weeks.

Procedure

This study is an eight week, randomized, parallel group trial. All the residents from intervention and control group were tested for measurements at baseline (week 0) and at week 8. A follow-up and final control after 12 weeks was conducted. The study was designed to evaluate the impact of individual pain treatment in NH residents with dementia.

At week 0 and week 8, residents were tested for BP, pulse rate, participation in NH`s social activities, skin observations/treatment, depression and QOL. At week 12 all the residents were treated for all the measurements except for depression and QOL (See figure 4).

Assessing and uncovering pain in dementia patients is challenging by the fact that these patients will neither be able to self-report pain or discomfort. Communication impairment has been identified as a major contributing factor to assess the pain relief

and side effects. If we are aware that pain may be causing the behaviors, the behaviors become understandable as a person's response to pain.

Therefore it is important that the treatment has to be individual, related to patient's possible pain problem.

Individual pain treatment

The individual pain treatment was carried out by Husebo et al. (2010). The pain treatment was performed by WHO and AGS guidelines (World Health Organization, 1993; AGS Panel, 1998). As per residents` need participants received maximum 1g X 3 Paracetamol, or 5mg X 2/d Dolcontin ret. (maximum increased to 10mg X 2/d), or in case of swallowing difficulties: Norspan plaster 5ug/hour/7d(maximum increase to 10ug/hour/7d); patients with neuropathic pain received 75mg X 1 Lyrica (maximum increased to 300mg/d). These doses are in consistent with the therapeutic efficacy and safety data of the drug manufacturers and previous research on Paracetamol, Dolcontine, Lyrica, and Norspan plaster in older patients with pain.

Measures

Skin Observation

Observation of skin was done by the caregivers on clinical bedside situation during morning care and all the skin problems including pressure sores, leg ulcers, diabetic foot ulcers and other kinds of skin rashes and infections like eczema, psoriasis and fungal infections were rated from 0 to 10 using Mobilization-Observation-Behavior-Intensity-Dementia-2 (MOBID-2) Pain Scale, where 0 indicates no skin problems and 10 indicates maximum skin problems.

MOBID-2 Pain Scale is two-part nurse-administered pain assessment tool, for older persons with dementia (Husebo, et al., 2008). In MOBID-2, the assessment of inferred pain intensity is based on patient`s pain behaviors in connection with standardized, guided movements of different body parts (Part 1) (Husebo, et al., 2007) and pain behaviors related to internal organs, head and skin registered on pain drawings and monitored over time (Part 2).

According to Husebo, et al. (2009) moderate to excellent kappa agreement was demonstrated for pain behavior and pain drawings. Moderate to excellent inter-rater and test-retest reliability was shown for pain intensity with good Cronbach`s α. Associations between nurses` ratings of patients` overall pain intensity by MOBID-2 and physicians` clinical examination were high.

Administration of MOBID-2 takes approximately 5 minutes (See attachment 1a & 1b).

Participation in Social activities

Most NHs have a calendar of activities, such as card tournaments, cinema nights, religious services, occasional guest singer, and Bingo, to prevent feelings of social isolation in residents. The range of activities should meet the needs of all residents, from the disoriented to the wheelchair bound to the ambulatory. NHs also provide therapy sessions to help older clients cope with additional free time, symptoms of disease or illness, loss of function. The therapy programs are used to reduce behavioral and psychiatric symptoms.

Measurement of participation of patients in NH`s social activities were done by using Observation Strategy by the caregivers and their participation was rated on a scale from 0 to 10 where 0 indicates that patients have not participated in social activities at all and 10 indicated maximum participation.

Benefits of secondary data collection is that observers were not aware of potential associations between pain treatment and residents` engagement in social activities. Thus, observers were "functionally blind" to the hypotheses of this study.

Blood Pressure and Pulse rate

Systolic blood pressure (SBP), diastolic blood pressure (DBP) and pulse rates were obtained from the left brachial artery with an automatic Digital Blood Pressure Monitor, Model UA-767 Plus 30, with measuring range from 20-280 mmHg. BP and pulse were measured on patients after having rested for five minutes.

Depression

The Cornell Scale for Depression in dementia (Alexopolous et al, 1988) was used to assess depression in people with dementia by means of 19 items rated on a three Point Scale, with a total score of 8 or over, indicating significant depressive symptoms.

Quality of life (QOL)

The Quality of Life in Alzheimer`s Disease Scale (QOL-AD) (Logsdon, et al., 2002) was used to measure QOL in dementia. It contained 13 items that included domains relevant to physical and mental health, personal relationships, finances and overall life quality. Higher scores indicated better QOL. The QOL-AD scale has been found to have good reliability and validity and can be used with people with mild, moderate and severe dementia (Thorgrimsen et al 2003; Hoe et al 2005).

Whenever possible, the patients were asked to complete the questionnaires independently to reflect their own views and experiences. However, the nurse or health care volunteer could assist with the process by reading the questions if necessary.

The QOL-questionnaire was translated to Norwegian language, and the same was back-translated into English before using the data for analysis, to confirm accuracy (See attachments 2 and 3).

Statistical Analyses

All statistical analyses were performed by using SPSS-18 for Windows, for quantitative analysis. Independent t-test was done to compare means and standard deviations between control and experimental groups with response to various measures. Paired sample t-test was done to compare the mean scores for the same group of people, control and experimental, on different occasions. Further, Pearson product moment coefficient for inter-correlations of scores among study variables in both control and experimental groups were done, followed by Regression analyses only in experimental group to understand variation in QOL as dependent variable with respect to other variables.

Figure 4: **Study flow chart.**

Pre-Screening
About 134 NH Patients were screened to find patients with dementia

About 66 Patients with Dementia were included in the study after following the inclusion procedures and informed consent

Patients were divided into 2 groups after randomization

Week 0 — Intervention Group (N=34) Pain Treatment Tests: BP, Pulse, skin, depression,

Control Group (N=32) Without focus on Pain Tests: BP, Pulse, skin, depression,

Week 8 — Tests: BP, Pulse, SA, skin, depression,

Tests: BP, Pulse, SA, skin, depression,

Week 12 — Follow-up Tests: BP, Pulse, SA, skin

Follow-up Tests: BP, Pulse, SA, skin

3.0 Results

Results from the descriptive analysis (table 1) showed that systolic blood pressure (BPS), diastolic blood pressure (BPD) and pulse rate did not show any significant difference between control and experimental group. Skin problems significantly reduced at week 8 and also at week 12 in experimental group, even though the intervention was

terminated at week 8. The participation in SA significantly increased at week 8 in experimental group, but there was no significant difference in participation in SA between control and experimental group at week 12. Depression level was significantly reduced and QOL scores were significantly increased in experimental group at week 8.

Table 2a shows mean comparisons at week 0, 8 and 12 for selected variables within control group, using Paired t-test. BPS, BPD and pulse rate did not show any significant difference between 0 versus 8, 0 versus 12 and 8 versus 12 week. Skin problems were significantly increased from 0 to 8 and from 0 to 12 week. Participation in SA was significantly reduced from 0 to 8 and 8 to 12 weeks. Depression level was significantly increased, whereas QOL score was significantly decreased from 0 to 8 weeks.

Table 2b shows mean comparisons at 0, 8 and 12 weeks for selected variables within experimental group using Paired t-test. BPS, BPD and pulse rate did not show any significant difference between 0 versus 8, 0 versus 12 and 8 versus 12 weeks. Pulse rate decreased non-significantly from 0 to 8 week, but increased significantly from 8 to 12 week, after the termination of intervention. Skin problems significantly reduced at week 8 and increased significantly from 8 to 12 weeks. Participation in SA significantly increased from 0 to 8 week and significantly reduced from 8 to 12 weeks. Depression level was significantly decreased and QOL score was significantly increased from 0 to 8 weeks.

To determine the associations among the study variables, Pearson product-moment correlations were computed. Tables 3a, 3b and 3c show Pearson product moment coefficients for inter-correlations of scores among study variables in control group at week 0, 8 and 12.

As shown in table 3a, BPD significantly and positively correlated with BPS at week 0. Pulse rate significantly and negatively correlated with BPS and BPD at week 0. Skin problems significantly and positively correlated with BPD at week 0. Table 3b shows that BPD significantly and positively correlated with BPS at week 8. Depression significantly and negatively correlated with participation in SA. QOL significantly and negatively

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correlated with skin problems at week 8. As shown in table 3c, BPD significantly and positively correlated with BPS at week 12. Skin problems significantly and positively correlated with BPS at week 12 and skin problems significantly and negatively correlated with pulse rate at week 12 in control group.

Tables 4a, 4b and 4c shows Pearson product-moment coefficients for inter-correlations of scores among study variables in experimental group at week 0, 8 and 12 respectively. Table 4a shows that BPD and pulse rate correlated significantly and positively with BPS at week 0. Pulse rate also correlated significantly and positively with BPD. Depression level correlated significantly and negatively with SA at week 0. QOL significantly and negatively correlated with depression level at week 0 in experimental group. Table 4b shows that pulse rate and BPD correlated significantly and positively with BPS at week 8. Pulse rate also correlated significantly and positively with BPD. Skin problems correlated significantly and negatively with BPD at week 8. Depression level correlated significantly and negatively with SA at week 8. QOL correlated significantly and negatively with depression at week 8 in experimental group. Table 4c shows BPD and pulse rate significantly and positively correlated with BPS at week 12. Pulse rate also correlated significantly and positively with BPD. Skin problems and SA did not show any significant correlations with other variables at week 12 in experimental group.

The associations between all the variables were also tested by using stepwise multiple regression analysis in experimental group as we did not expect any changes in control group. Regression analysis was performed in experimental group with simultaneous entry of all predictor variables, so regression coefficients represent the unique contribution of a variable in the full model, controlling for the other variables (Table 5a and 5b).

Results from the multiple regression analysis, as shown in table 6 for the whole sample showed that depression was significantly and negatively associated with QOL with a $\beta= -0.366$ and pulse rate was significantly and positively associated with QOL with a $\beta= 0.091$. The other variables, BPS, BPD, skin problems and participation in SA were not significantly associated with QOL in the multiple regression analysis (see figure 5).

Figure 5. Pulse rate and depression as the ultimate manifestation of QOL.
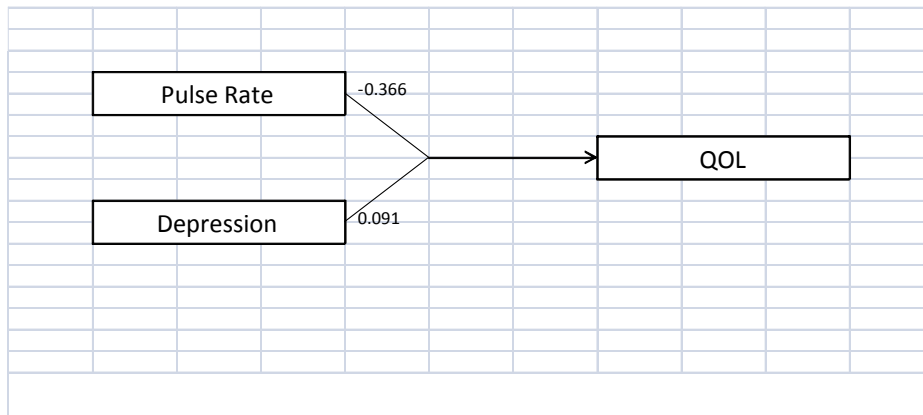
4.0 Discussion

The purpose of this study was to investigate the impact of pain intervention on the QOL of patients with dementia, residing in NHs. Pain is a variable that is consistently missing from the various contemporary definitions of QOL. Research in pain and its correlation to QOL in NH residents is lacking, even though there is plenty of research about prevalence of pain among NH residents, hence the present study.

The mean comparisons between control and experimental groups has clearly shown that the skin problems in the experimental group was significantly improved. Residents belonging to experimental group socialized more in NH environment, their depression levels had reduced and their QOL scores were increased at the end of intervention period. The explanation for high levels of depression, increased skin problems and refusing to socialize in NH environment and ultimately low scores of QOL at baseline in both control and experimental groups could be related to pain. Pain is generally acknowledged to be a complex, subjective phenomenon that encompasses nociceptive, perpetual, cognitive and emotional factors (Loeser, 1980; Turk et al., 1983). Pain interfered with different domains of the patient`s life or disrupted his or her functioning (Cleeland & Syrjala, 1992). When functional abilities are impaired, it ultimately increases depression level as it was seen in residents before the intervention, at baseline, as supported by Clifford et al. (2003). Due to impairment in functional abilities and increased depression level, NH residents rated low QOL at baseline.

QOL renders explicit that long-held conviction within medicine that no goal can be more important than the patient`s well- being (Cella, 1994) and highlights the goal by complementing the emphasis on the patient`s functioning by an emphasis on patient`s subjective well-being. Though this insight has come to play an increasing role in all medical fields, in the domain of pain its implementation may have been more difficult, because pain has been commonly considered as an integral part of QOL itself (Portnoy, 1990). Thus, the additional conceptual step of abstracting pain from the complex of QOL was necessary before the question about the impact of pain on QOL could be clearly posed.

In the present study, the resident`s rating of their own QOL were highly associated with symptoms of depression, in consistent with studies done by Nagamoto et al (1997). QOL scores were inversely and significantly correlated with depression level in experimental group at the end of the intervention period. Depression, on the other hand, was significantly and negatively correlated with pulse rate and BPS and significantly and positively correlated with participation in NH`s activities. The main result from the multiple regression analysis showed that depression level and pulse rate were significantly associated with QOL. In this connection, it can be hypothesized that pain could be one of the factors which affected the mood and pulse rate of the residents. Due to pain, functional ability of residents was reduced; therefore they could not socialize and isolated themselves and thereby rating their QOL scores low. In short, it can be said that lower levels of depression and higher levels of functional abilities, social contact and social activities were found to be related to higher scores of QOL in dementia, which is in consistent with the studies done by Logsdon et al (1999) and Bergener & Twigg (2002). Conversely, low QOL was linked to poor physical health and memory, loss of role, increased boredom and loneliness (Ready et al., 2002). Some other studies suggested that QOL in dementia is influenced by mood and environmental factors independent of dementia severity (Hoe et al., 2005; Thorgrimsen et al., 2003). Kunik et al (1998) suggested that improvement in depression, contributes to improvement of specific behavior disturbances, which is in consistent with the present study. We hypothesized that cognitive impairment, although not having a direct link to QOL, is likely to be mediated by behavioral disturbances. In the present study, pain treatment reduced depression level, followed by improvement in behavioral disturbances. By improvement in behavioral

disturbances, patients were more cooperative, thereby it was possible to examine their skin problems.

There has been growing evidence that the experience of living with a chronic wound has a huge impact on patient`s QOL (Masuda et al., 2010; Jorgensen, 2006). These studies are consistent with the present study where it was found that in control group, skin problems were negatively correlated with QOL. Paired t-test showed that the skin problems decreased significantly in experimental group at week 8. Pain, whether it is age-related or related to skin problems is one of the symptoms that patient find particularly distressing and that in turn, affects patient`s co-morbidities, functional state, nutritional status, socialization and ultimately QOL. It could be interpreted that chronic wound related pain was positively related with high levels of affective distress and depressive symptoms as supported by Roth & Robbins (2004). Due to increased depression levels, residents isolated themselves and refused to take part in social activities, as depression levels correlated significantly and negatively with SA in the present study. Under-treatment of all types of acute and chronic wounds in elderly is common. Therefore, early control of wound pain may improve the patient`s psychological state and is thought to have an impact on wound healing, which ultimately make residents to socialize actively. Health professionals are now starting to recognize the importance of addressing the issue of wound pain, as evidenced by the European Wound Management Association Position Document (EWMA, 2002) on pain.

Although only limited work has been completed on pain in chronic wounds, much of this has focused on pain in dressing change (Moffatt et al., 2002). In the present study, in experimental group, at week 8, the skin problems showed significant improvement, but it negatively correlated with pulse rate. Wounds were healing, but pulse rate was higher, as dressing change, especially in elderly people with particularly fragile skin, the removal of dressings that stick to the wound may well be the most painful part of the dressing procedures, as supported by Brigg et al. (2002), which in turn increases the pulse rate. There are statistical differences between the wound types, with venous, arterial and mixed ulcers reporting more frequent pain as residents included in the study experienced. The most wound pain was experienced in the wound itself, whereas some residents experienced dressing-related pain most or all the time. Some residents reported that it took longer than one hour for this pain to resolve. NH residents included in the study were given painkillers

before the dressing change. Thus our data support the growing awareness of pain associated with the cleansing part of the procedure, as reported by Lindholm (2007) and Woo et al (2007).

Ample evidence shows that ageing is associated with high rate of painful conditions, irrespective of cognitive status (Horga & Elliot, 2004). Chronic pain leads to chronic stress, which in turn, can affect many of body`s immune systems, as can an individual`s perception of, and reaction to stress. Immune system changes can create more vulnerability to infection to increase the potential for an outbreak of psoriasis for people with skin disorders. In addition to pain, when there was an outbreak of skin disorders in study residents, it led to increased agitation in control group. Due to agitation, residents were less cooperative, which made skin observation and treatment difficult for the NH staff. This ultimately resulted in increased skin problems.

The disruptive behaviors often indicate discomfort in the person with dementia, and are major sources of stress (Cohen-Mansfield & Mintzer, 2005). Responses to stress include adaptation, psychological coping such as stress management, anxiety and depression. Over a long time, distress can lead to diminished health and/or increased propensity to illness; to avoid this, stress must be managed. A high level of stress impairs people`s memory and attention during cognitive activities (Cohen-Mansfield & Billig, 1986). Cognitive appraisal processes can influence both the stress and emotional experience, for example fear and anger, which is common emotional reaction. When stress is accompanied by anger, negative social behaviors tend to increase as it was observed clearly in present study among residents of control group.

One-third of persons with dementia have depressive symptoms, and concomitant behavioral and psychological symptoms are very likely (Prado-Jean et al., 2010). In the present study, depression level of NH residents in control group was significantly increased, accompanied by significant increase in skin problems and significant reduction in participation in SA, contrary to experimental group. In experimental group, and at the end of intervention, pulse rate decreased even though non-significantly, clearly indicating that pain was the major stress factor. Petrovik et al (2007) has shown that apathy and depression were the most common abnormalities in people with dementia, followed by irritability, anxiety and

agitation. In this connection, it could be argued that there might be causal relations underlying the same cross-sectional association of bodily symptoms, depression and anxiety; for example, in the present case, anxiety and depression might be a reaction to bodily pain and distress, in others, depression and anxiety may lower the threshold for reporting bodily symptoms. There might also be potent common genetic and environmental causal factors underlying bodily as well as psychological dimensions of distress (Gillespie et al., 1999). Psychological support is modifier of stress. Esteem support is especially important during the appraisal of stress, when the individual is assessing whether the demands exceed their personal resources. A person`s capacity to tolerate the source of stress may be increased by thinking about another topic such as hobby, listening to music or socializing with other residents in NH environment.

In the present study, even though residents belonging to experimental group were treated for pain, it was difficult to engage them in NH`s social activities in the beginning of the intervention period. We should not expect that NH residents will be more socially engaged than the population at large; functional impairments clearly limits residents` opportunities to pursue involvement in the activities (Mor et al., 1995). Our aim was to target social and recreational programs for residents that are appropriate to their level of function and which offer them meaningful involvement in their environment.

The core objective of NH staff has long been to provide the residents with high quality care, for example, the absence of markers of poor health care (Kane et al., 2003). In recent years, however, not only quality of care, but also QOL – as experienced by the residents – is becoming increasingly accepted as an important objective of care (Rijckmans et al. 2005). QOL is indicated not only by a relatively good medical and functional health status, but also perhaps even more so by psychological and social well-being (Gerritsen et al., 2004). Although researchers disagree on the content of QOL, most agree that it is about well-being, or the subjective experience of life. Psychological and social well-being are important domains in most approaches, the former often considered as the central outcome (Gerritsen et al., 2007).

One of the aims of the present study was to engage NH residents in social activities as nowhere in the enormity of the impact of social support potentially more critical than in the

institutionalized elderly. Repeatedly researchers have reported on the health benefits resulting from social support (Cohen-Mansfield, 2000; Siebert & Mutran, 1999). Formal and informal NH activities seemed uninteresting to most of our residents and seemed to be a poor stimulant of socialization. An argument could be made that resident debility due to pain was the contributing factor leading to the observed inertia at the beginning of the intervention period. Certainly, debility results in decreased participatory ability and limits the array of activities that might be employed as entertainment which was clearly seen in residents of control group throughout the study and those belonging to experimental group in the beginning of the study. However, by definition, the word "entertainment" suggests a passive activity, whereby the person, in the case of NH resident, receives a diversion and does not necessarily provide social interaction. The pain, illness, confusion, dementia and the depressive symptoms are the main responses for the discouraged interactions as suggested by Schneider et al. (2002). In order to encourage the interactions, we held exercise classes, focused on staff acknowledgement of residents` individuality and we emphasized on friendly and kind staff approach to residents. In the present study, the social activities included homelike atmospheres, independence, reciprocity and activities that promoted interactions, in consistent with studies done by Reed-Danahay (2001).

We also tried to follow the intervention employed by Cohen-Mansfield (2010) that involved objects or tasks with meaning specific to the person with dementia which most likely engaged the person. By the use of such interventions in the present study the participation of NH residents in SA increased significantly in experimental group at the end of intervention. The participation in SA was reduced from week 8 to 12 when intervention was terminated. Mean comparisons also showed that in experimental group at week 8, depression level had reduced, accompanied by increased QOL score. There is an interplay between pain, participation in SA, depression and QOL, which could be interpreted that due to pain treatment residents` functional level increased thereby reducing depression level and increasing participation in SA which ultimately increases QOL score. Correlation coefficient analysis showed that in control group the participation of residents in SA were negatively correlated with depression levels. On the other hand, depression level was reduced in experimental group at week 8. In consistent with study done by William and Tappen (2008), we engaged patients in comprehensive exercise routine, which had

beneficial effect on depression. Depression was reduced in patients with some evidence of superior benefit from exercise; as seen by coefficient correlation analysis that participation in SA negatively correlated with depression. Traditionally, social well-being aspects of NH residents are assessed according to the social activities and interactions where the residents engage, for example Functional behavior profile (Baum et al., 1993), Index for social engagement (Mor et al., 1995) and Activity and Affect Indicators (Albert et al., 1996). These are important indicators of social well-being, but other important indicators may be positive social behavior of others may make an important contribution to the residents` overall social well-being. This is because social well-being is a result of the behavior of the resident and behavior of the people around the resident, including the NH staff. This part of the study is supported by Gerritsen et al (2010) and Steverink & Lindenberg, (2006). The combination of these social behaviors is assumed to reflect positive social well-being of NH residents, which was clearly observed at the end of the intervention period in experimental group, accompanied by reduction in pulse rate. Just as there are basic needs, there may also be basic social needs, that is fulfilled, yield social well-being, and ultimately enhanced QOL.

The purpose of including the BP and pulse measures in this study was to provide some additional evidence, over and above a placebo effect, for the benefit of pain treatment. It was reasoned that if pain perception truly declined following the pain treatment, we should also see drops in BP and pulse rate as it was hypothesized. Although BP and pulse rate response to pain has been studied, no study has been published on BP and pulse responses to the relief of acute and chronic pain in NH settings.

In the present study, Independent t-test showed that BPS was non-significantly reduced in experimental group at week 8 whereas significantly reduced at week 12, even though pain treatment was terminated at week 8. In this connection, it could be said that while pain from injury causes a surge of adrenalin, and a rise in BP, usually chronic pain does not. The adrenalin level falls back to normal and BP as well. The relationship between chronic pain and BP is much less well understood. The reason that there was non-significant difference in BP after the intervention could be that there may be a deficiency of endogenous opioids in the chronic pain patients. In the present study, at week 12 in control group, BP was significantly higher than experimental group at week 12 and this group was not treated for

pain at all. The results indicated that the residents who reported higher pain had a higher BP.

In the present study, there was non-significant difference in BPS in experimental group at week 8, even though they were treated for pain, could also be explained on the basis of long term use of anti-inflammatory drugs, which increases BP, by affecting kidney`s ability to get rid of water and salt. Other explanation for higher BP could be anxiety, which is an emotional reaction , cannot be perceived cautiously and includes tension, worry and fear (Kim & Kwon, 2010). While a general fair level of anxiety makes a person adapt to a circumstance by awaking them, an excessive and continuous anxiety can result in maladjustment by reducing one`s ability to cope with a certain circumstances (Lee, 2009). Further coefficient correlation analysis showed that BPS correlated positively with BPD at week 8 and 12 in control group and BPS and BPD correlated positively with skin problems at week 12 in control group and BPS, BPD correlated positively with pulse rate.

It is clear that there is a close but invariable relationship between pain sensitivity and BP. The higher BP in control group at week 12 could be a learned behavior pattern that would reduce the effect of stress.

The pulse rate reduced non-significantly at week 8 in experimental group, but increased again non-significantly at week 12. Paired t- test showed that pulse rate increased significantly from week 8 to 12 week in experimental group. Pain increases pulse rate via autonomic nervous system stimulation and catecholamines release. However, pain is a subjective experience, influenced by many psychologic and sociologic factors including past experience, cultural learning, anxiety and depression (Rosenzweig, 2001). At the end of intervention when the residents were with reduced pain, their depression level and skin problems had reduced and they were evaluated for decreased pulse rate. Also regression analysis showed that pulse rate was significantly associated with QOL.

Pulse rate measurement was useful in clinical practice to indicate the presence of pain in patients unable to communicate secondary to age or cognitive impairment. The results from the present study were consistent with our assumptions in several ways and indicated that the pain intervention increased the QOL of patients, residing in NHs.

The present study supports the conceptualization that QOL in NH residents is a process composed of many variables, for example, the physical, physiological and psychological, such as pain due to chronic illness and wounds, depression, BP, pulse rate and socialization that interacts with one another to predict patient`s QOL. Interestingly, pulse rate that in turn depends on the pain, indirectly is the predictor of QOL along with reduced depression. Thus residents with cognitive impairments who have difficulty expressing their pain may manifest through salient outlets such as pulse rate measurements and depression.

5.0 Conclusion

This study is an important step in understanding how certain QOL variables are related to one another. The most interesting result of this study showed that despite residents having dementia, residents` views of their own QOL were strongly linked to their mood, in terms of depression. The study also reports that there is an association between patient`s report of pain severity and stress- related changes in vital signs such as pulse rate. The findings suggest that treating chronic pain and painful wounds is likely to enhance the QOL indicators for overall well-being of patients residing in NH settings. A challenge for the direct assessment of QOL in people with dementia is the apparent lack of insight, such as self-care, memory, health status, language abilities (Green et al., 1993; Vasterling et al., 1995) and cognitive deficits. However, Brod et al (1999) suggests that awareness of feelings may be preserved even in instances where awareness of cognitive deficits is impaired. The present study suggested that people with dementia can respond accurately to questions about QOL and can articulate feelings, concerns and preferences and provide evaluations of their health and QOL, in consistency with previous studies (Mc Horney, 1996; Mozley et al, 1999; Feinberg & Whitlatch, 2001; Logsdon et al, 2002, Smith et al, 2005). In the present study the residents were able to complete the item pool of QOL-AD with no missing data, which suggested that people with dementia are able to respond approximately to QOL questions and express these responses using a standardized response scale.

In the past, the recognition and treatment of pain in people with dementia has been poor. Carers have a vital role in observing and reporting pain to medical staff. Often they can anticipate a person`s needs and ensure their comfort. Nursing staff, nursing assistants and

families need to be educated about the importance of assessing and fully treating pain and their role in pain assessment. Inadequate treated pain leads to problematic behaviors and inappropriate prescription of sedatives and tranquilizers. Pain may decrease functional ability, worsen memory problems and delay recovery of wounds. It may disrupt the person`s sleep, causing depression and social withdrawal. Appropriate pain treatment, accurately titrated per the patient`s need, rests on the foundation of accurate and timely pain assessment. Simple pain treatment can give great relief and dramatically improve QOL.

6.0 Implication, Limitation and Further Research

The present study has clinical implications for maximizing QOL in NH settings where residents with cognitive impairment and chronic pain require varying levels of assistance in daily life. Figures 2 and 3 also suggest that concurrent to treatment interventions, chronic pain need to be routinely treated or managed in order to reduce depression and normalize pulse rate that interferes with QOL. Multidisciplinary evaluation should assess individual differences and coordinate interdisciplinary treatment in order to maximize QOL in NH residents.

There are several limitations to this study. There were several patients who were taking medications for hypertensive blood pressure with possible chronotropic effects and were not excluded. The effect of specific injury, illness and fever on pulse rate, untreated to pain was also not controlled for. Another limitation is that the timing of observations centered on periods of high verbal interaction, not necessarily on when residents would likely to engage in activities.

Our samples consisted largely of chronically ill-residents with dementia and some of them also had behavioral problems, interfering with QOL. Thus, there are limitations in the extent to which we can generalize our findings to the general NH population.

Further research is required to determine the minimum cognitive requirements needed to complete QOL-AD assessment and to assess depression, pain and socialization of patient with mild, moderate and severe dementia, individually and comparatively. Future research should consider how the individual`s QOL changes as the dementia process progresses. It

would also be of interest to look at QOL of residents with dementia compared with residents without dementia who live in the same NH. Further qualitative research could also explore in more depth which factors influence a person with dementia`s QOL.

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Part 2

Article

Efficacy of Individual Pain Treatment on Quality of Life of Patients with Dementia in Nursing Homes.

By

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Abstract

This study focuses on the impact of individual pain treatment on the quality of life of nursing home residents in west-coast of Norway. About 66 residents were recruited from five nursing homes and they were subjected to randomization. After randomization, residents were divided into two groups; the intervention group, where residents were given individual pain treatment for the period of eight weeks, and control group, where residents were not treated for pain. At the end of the next four weeks, after the intervention period, some of the measures were repeated in both the groups, as a follow up study. The variables measured to study the quality of life were, systolic blood pressure, diastolic blood pressure, pulse rate, participation in social activities, skin problems and depression. The major findings from stepwise-regression analysis in experimental group indicated that pulse rate and depression were the ultimate predictors of quality of life of nursing home residents with dementia. The findings suggest that treating chronic pain and painful wounds is likely to enhance the quality of life indicators for overall well-being of patients residing in nursing homes.

Keywords: Blood pressure, Dementia, Depression, Geriatrics, Nursing homes, Pain, Pulse rate, Psychosocial, Quality of life, skin problems and wounds

Introduction

It is estimated that 24.3 million people have dementia today, with 4.6 million new cases of dementia every year (1). In Norway, the number of people with dementia is approximately 70,000, and the number is expected to double within the next 30 years (2). In nursing homes (NHs), 80% of the patients have dementia, and behavioral and psychiatric disturbances is one of the hallmark symptoms of dementia (3, 4). Common behavioral and psychiatric disturbances in dementia include depression, apathy, withdrawal, irritability, agitation, aggression, wandering, change in sleep pattern, socially disruptive behavior and sun downing syndrome (5, 6). Such disruptive behaviors often indicate discomfort or pain in the person with dementia, and are major sources of stress. Stress exacerbates the symptoms and course of many chronic illnesses, and since depression is a common consequence of stress, reducing stress levels and managing those stressors that cannot be eliminated are paramount for the management of chronic illness.

Pain has been highlighted as a significant problem for many old people and further, they are more susceptible to the experience of pain than the younger generation of the population (7, 8). This is partly due to the high prevalence of musculoskeletal disorders, phantom pain, pressure ulcers, cancer and other medical conditions in this age group (9). Wounds are the significant problem at the end of life of NH residents. Unsurprisingly, the majority of wounds are pressure ulcers, but ischemic wounds, diabetic foot ulcers, venous stasis ulcers are also significant. Pressure ulcer risk is increased with poor nutrition, immobility, loss of cognitive function, and incontinence (10), all of which are seen in the end-of-life population. Some wounds result in chronic discharging wounds that cause pain and impact upon quality of life and social function.

In most nursing home residents, due to incurable chronic diseases, complaints of pain range is in prevalence from 45% to 83% (11,12,13,14,). Despite the NH residents exhibiting a high prevalence of pain, and functional disability, which is potentially made worse by pain (15), pain remains unidentified and untreated by nursing home staff (16, 17). The experience of living with a chronic pain has a significant impact on residents` quality of life (QOL).

Quality of life commonly defined as "the individual`s perceptions of his or her position in life, in the context of the culture and value systems in which he or she lives, and in relation to his

or her goals, expectations, standards and concerns (18), or in more general and operational terms, as the individual`s perceptions of his or her functioning as well-being in different domains of life (19). These definitions highlights the difference between QOL and the individual`s functional status, which measures how the pain objectively affects the patient`s physical and emotional functioning and capabilities. Treatment designed to reduce pain may be expected to affect QOL favorably.

Even when older people report pain, most studies have identified an alarming trend towards leaving pain untreated in as many as 85% of old people with identified pain and/or pain causing diagnoses (20). Failing to adequately treat pain can lead to host of problems and can make the person with dementia susceptible to worsened health as well as poor quality of life. Although, plenty of research work is done recognizing the pain in nursing home residents, little work has focused on the QOL experienced by NH residents. Hence the present study was planned to study the impact of individual pain treatment on QOL of NH residents with dementia.

Methods

The present study is a part of a larger cluster randomized trial (21).

This study is approved by REK-Vest and the Data Inspectorate. The conduct of the study was in accordance with the medical research Council Guidelines for Clinical Practice in Clinical trial (22).

Study Population

About 134 NH patients were screened from about 5 NHs from west coast of Norway to find patients with dementia. Patients were included in the study after they met all the inclusion criteria. The inclusion criteria were that the resident was more than 60 years old, residing in nursing home for at least 3 months, and had dementia according to Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (23).

Sample

After screening, about 66 patients with dementia were selected for the study. After obtaining the informed consent from all the participants and/or their relatives, patients were included in the study and they were subjected to randomization. Patients were randomized into two groups:

Intervention Group: This group consisted of 34 patients who were given individual pain treatment based on pain assessment by Mobilization-Observation-Behavior-Intensity-Dementia-2 Pain Scale (MOBID-2) (24), for the period of 8 weeks.

Control Group: This group consisted of 32 patients who were not treated for pain but medical management for physical and psychiatric disease was routinely done without active management of pain for the period of 8 weeks.

Procedure

This study was an eight week, randomized, parallel group trial. All the residents from intervention and control group were tested for measurements at baseline (week 0) and at week 8. A follow-up and final control after 12 weeks was conducted. The study was designed to evaluate the impact of individual pain treatment in NH residents with dementia.

At week 0 and week 8, residents were tested for blood pressure, pulse rate, participation in NH`s social activities, skin observations/treatment, depression and QOL. At week 12, all the residents were treated for all the measurements except for depression and QOL.

Assessing and uncovering pain in dementia patients is challenging by the fact that these patients will neither be able to self-report pain or discomfort. Communication impairment has been identified as a major contributing factor to assess the pain relief and side effects. If we are aware that pain may be causing the behaviors, the behaviors become understandable as a person`s response to pain.

Therefore it is important that the treatment has to be individual, related to patient`s possible pain problem.

Individual pain treatment

The individual pain treatment was carried out by Husebo et al (21). The pain treatment was performed by WHO and AGS guidelines (25, 26). As per residents` need, participants received maximum 1g X 3 Paracetamol, or 5mg X 2/d Dolcontin retard (maximum increased to 10mg X 2/d), or in case of swallowing difficulties: Norspan plaster 5ug/hour/7d(maximum increase to 10ug/hour/7d); patients with neuropathic pain received 75mg X 1 Lyrica (maximum increased to 300mg/d). These doses are in consistent with the therapeutic efficacy and safety data of the drug manufacturers and previous research on Paracetamol, Dolcontine, Lyrica, and Norspan plaster in older patients with pain.

Measures

Skin Observation

Observation of skin was done by the caregivers on clinical bedside situation during morning care, and all the skin problems including pressure sores, leg ulcers, diabetic foot ulcers and other kinds of skin rashes and infections like eczema, psoriasis and fungal infections were rated from 0 to 10 using MOBID-2 instrument, where 0 indicates no skin problems and 10 indicates maximum skin problems.

MOBID-2 Pain Scale is a staff- administered behavioral instrument for assessment of pain in older persons with dementia (24). MOBID -2 is based on patient`s pain behavior in connection with standardized, guided movements of different body part and pain behavior related to internal organs, head and skin. Administration of MOBID-2 takes approximately 5 minutes (See attachment 1a and 1b).

Participation in Social activities

Measurement of participation of patients in NH`s social activities were done by using Observation Strategy by the caregivers and their participation was rated on a scale from 0 to 10 where 0 indicated that patients have not participated in social activities at all and 10 indicated maximum participation.

Benefits of secondary data collection are that observers were not aware of potential associations between pain treatment and residents` engagement in social activities. Thus observers were "functionally blind" to the hypotheses of this study.

Blood Pressure and Pulse rate

Systolic blood pressure, diastolic blood pressure and pulse were obtained from the left brachial artery with an automatic Digital Blood Pressure Monitor, Model UA-767 Plus 30, with measuring range from 20-280 mmHg. Blood pressure and pulse were measured on patients after having rested for five minutes.

Depression

The Cornell Scale for Depression in dementia (27) was used to assess depression in people with dementia by means of 19 items rated on a three Point Scale, with a total score of 8 or over indicating significant depressive symptoms.

Quality of life (QOL)

The Quality of Life in Alzheimer`s Disease Scale (QOL-AD) (28) was used to measure QOL in dementia. It contained 13 items which include domains relevant to physical and mental health, personal relationships, finances and overall life quality. Higher scores indicated better QOL. The QOL-AD scale has been found to have good reliability and validity and can be used with people with mild, moderate and severe dementia (29,30).

Whenever possible, the patients were asked to complete the questionnaires independently to reflect their own views and experiences; however, the nurse or health care volunteer could assist with the process by reading the questions if necessary. In this study, emphasis was on the patient`s subjective experience of their QOL as NH-resident.

The QOL-questionnaire was translated to Norwegian language, and the same were back-translated into English before using the data for analysis, to confirm accuracy (see attachments 2 & 3).

Statistical Analyses

All statistical analyses were performed by using SPSS-18 for Windows for quantitative analysis. Independent t-test was done to compare means and standard deviations between control and experimental groups with response to various measures. Paired sample t-test was done to compare the mean scores for the same group of people, control and experimental, on different occasions. Further Pearson product moment coefficient for inter-correlations of scores among study variables in both control and experimental groups were done, followed by Regression analyses in experimental group, to understand variation in QOL as dependent variable with respect to other variables.

Results

Results from the descriptive analysis showed that systolic blood pressure, diastolic blood pressure and pulse rate did not show any significant difference between control and experimental group. Skin problems significantly reduced at week 8 and also at week 12 in experimental group, even though the intervention was terminated at week 8, and participation in social activities significantly increased at week 8 in experimental group. Depression level was significantly reduced and QOL scores were significantly increased in experimental group at week 8.

Table 1 about here

Table 2a shows mean comparisons at week 0, 8 and 12 for selected variables within control group, using Paired t-test. Systolic blood pressure, diastolic blood pressure and pulse rate did not show any significant difference between 0 versus 8, 0 versus 12 and 8 versus 12 week. Skin problems were significantly increased from 0 to 8 and from 0 to 12 week. Participation in social activities was significantly reduced from 0 to 8 and 8 to 12 weeks. Depression level was significantly increased, whereas QOL score was significantly decreased from 0 to 8 weeks.

Table 2a about here

Table 2b shows mean comparisons at 0, 8 and 12 weeks for selected parameters within experimental group using Paired t-test. Systolic blood pressure, diastolic blood pressure and pulse rate did not show any significant difference between 0 versus 8, 0 versus 12 and 8 versus 12 weeks. Pulse rate decreased non-significantly from 0 to 8 week, but increased significantly from 8 to 12 week, after the termination of intervention. Skin problems significantly reduced at week 8 and increased significantly from 8 to 12 weeks. Participation in social activities significantly increased from 0 to 8 week and from 8 to 12 weeks. Depression level was significantly decreased and QOL score was significantly increased from 0 to 8 weeks.

Table 2b about here

To determine the associations among the study variables, Pearson product-moment correlations were computed. Tables 3a, 3b and 3c shows Pearson product- moment coefficients for inter-correlations of scores among study variables in control group at week 0, 8 and 12. As shown in table 3a, diastolic blood pressure significantly and positively correlated with systolic blood pressure, pulse rate significantly and negatively correlated with systolic and diastolic blood pressure at week 0.

Table 3a about here

Table 3b shows that diastolic blood pressure significantly and positively correlated with systolic blood pressure at week 8. Depression level significantly and negatively correlated with participation in social activities. QOL significantly and negatively correlated with skin problems at week 8.

Table 3b about here

As shown in table 3c, diastolic blood pressure significantly and positively correlated with systolic blood pressure at week 12. Skin problems significantly and positively correlated with systolic blood pressure at week 12 and skin problems significantly and negatively correlated with pulse rate at week 12 in control group.

Table 3c about here

Tables 4a, 4b and 4c show Pearson product-moment coefficients for inter-correlations of scores among study variables in experimental group at week 0, 8 and 12 respectively. Table 4a shows that diastolic blood pressure and pulse rate correlated significantly and positively with systolic blood pressure at week 0. Pulse rate also correlated significantly and positively with diastolic blood pressure at week 0. Depression level correlated significantly and negatively with participation in social activities. QOL significantly and negatively correlated with depression at week 0 in experimental group.

Table 4a about here

Table 4b shows that diastolic blood pressure and pulse rate correlated significantly and positively with systolic blood pressure at week 8. Pulse rate also correlated significantly and positively with diastolic blood pressure at week 8. Skin problems significantly and negatively correlated with participation in social activities, whereas QOL significantly and negatively correlated with depression at week 8, in experimental group.

Table 4b about here

Table 4c shows that Pulse rate and diastolic blood pressure correlated significantly and positively with systolic blood pressure at week 12. Pulse rate also significantly and positively correlated with diastolic blood pressure at week 12 in experimental group.

Table 4c about here

The associations between all the variables were also tested by using stepwise multiple regression analysis in experimental group as we did not expect any changes in control group. Regression analysis was performed in experimental group with simultaneous entry of all predictor variables, so regression coefficients represent the unique contribution of a variable in the full model, controlling for the other variables as shown in table 5a and 5b.

Table 5a and Table 5b about here

Results from the multiple regression analysis for the whole sample showed that depression was significantly and negatively associated with QOL and pulse rate was significantly and positively associated with QOL (Table 6). The other variables, systolic and diastolic blood pressure, skin problems and participation in social activities were not significantly associated with QOL in the multiple regression analysis.

Table 6 about here

Discussion

The purpose of this study was to investigate the impact of pain intervention on the QOL of patients with dementia, residing in NHs. Research in pain and its correlation to QOL in NH residents is lacking, even though there is plenty of research about prevalence of pain among NH residents, hence the present study was planned.

The mean comparisons between control and experimental group showed that the skin problems significantly improved at week 8 in experimental group. The participation in NH`s social activities increased significantly in experimental group compared to control group at the end of intervention. The depression level and QOL scores showed significant improvement at the end of intervention period compared to baseline. The explanation for high levels of depression, increased skin problems and refusing to socialize in NH environment and ultimately low scores of QOL at baseline in both control and experimental groups could be related to pain. Pain interfered with different domains of the patient`s life or disrupted his or her functioning (31). The main result from the multiple regression analysis showed that depression level was significantly associated with QOL. Due to pain, functional ability of residents was reduced; therefore they could not socialize and isolated themselves, and thereby rating their QOL scores low. In short, it can be said that lower levels of depression and higher levels of functional abilities, social contact and social activities were found to be related to higher scores of QOL in dementia, which is in consistent with the studies done by Logsdon et al. (32) and Bergener & Twigg (33). Some studies have suggested that QOL in dementia is influenced by mood and environmental factors independent of dementia severity (29, 30). Kunik et al (34) suggested that improvement in depression contributes to improvement in specific behavior disturbances as we have seen in the present study. We hypothesized that cognitive impairment, although not having a direct link to QOL, is likely to be mediated by behavioral disturbances. In the present study, pain treatment reduced depression level, followed by improvement in behavioral disturbances.

By improvement in behavioral disturbances, patients were more cooperative, thereby it was possible to examine their skin problems.

The present study showed that in control group skin problems were negatively correlated with QOL. There has been growing evidence that the experience of living with a chronic wound has a significant impact on patients` QOL (35, 36). Paired t-test showed that the skin problems decreased significantly in experimental group at week 8. Pain, whether it is age-related or related to skin problems is one of the symptoms that patient find particularly distressing and this in turn affects patient`s co-morbidities, functional state, nutritional status, socialization and ultimately QOL. It could be interpreted that chronic wound related pain was positively related with high levels of affective distress and depressive symptoms as supported by Roth & Robbins (37). Due to increased depression levels, residents isolated themselves and refused to take part in social activities, as depression levels correlated significantly and negatively with participation in social activities in the present study. Under-treatment of all types of acute and chronic wounds in elderly is common. Therefore, early control of wound pain may improve the patient`s psychological state and is thought to have an impact on wound healing, which ultimately make residents to socialize actively.

In the present study, in experimental group, at week 8, the skin problems showed significant improvement, but it negatively correlated with pulse rate. Wounds were healing, but pulse rate was higher, as dressing change, especially in elderly people with particularly fragile skin, the removal of dressings that stick to the wound may well be the most painful part of the dressing procedures, as supported by Brigg et al. (38), which in turn increases the pulse rate. There are statistical differences between the wound types, with venous, arterial and mixed ulcers reporting more frequent pain as residents included in the study experienced. The most wound pain was experienced in the wound itself, whereas some residents experienced dressing-related pain most or all the time. Some residents reported that it took longer than one hour for this pain to resolve. NH residents included in the study were given painkillers before the dressing change. Thus our data support the growing awareness of pain associated with the cleansing part of the procedure, as reported by Lindholm (39) and Woo et al. (40).

NH residents suffering from chronic wounds have chronic pain. Chronic pain leads to chronic stress, which in turn, can affect many of body`s immune system. Immune system changes can create more vulnerability to infection to increase the potential for an outbreak of psoriasis for people with skin disorders. The skin disorders led to agitation among NH residents, which made skin observation and treatment difficult for the NH staff. This ultimately resulted in increased skin problems as was observed in control group. Due to increased skin problems, residents isolated themselves and refused to participate in NH`s social activities.

One-third of persons with dementia have depressive symptoms, and concomitant behavioral and psychological symptoms are very likely (41). In the present study depression level of NH residents in control group was significantly increased, accompanied by significant increase in skin problems and significant reduction in participation in social activities, contrary to experimental group. In experimental group, and at the end of intervention, pulse rate decreased even though non-significantly, clearly indicating that pain was the major stress factor. Petrovik et al (42) has shown that apathy and depression were the most common abnormalities in people with dementia, followed by irritability, anxiety and agitation. In this connection, it could be argued that there might be causal relations underlying the same cross-sectional association of bodily symptoms, depression and anxiety; for example, in the present case, anxiety and depression might be a reaction to bodily pain and distress. However, in contrast to the present study, the findings of Murberg et al (43) has indicated that depression among heart failure patients is not primarily related to severity of chronic heart failure illness, nor to the somatic symptoms of dyspnea, but rather to the perception of impairment in activities of daily living. Psychological support is modifier of stress. Esteem support is especially important during the appraisal of stress, when the individual is assessing whether the demands exceed their personal resources. A person`s capacity to tolerate the source of stress may be increased by thinking about another topic such as hobby, listening to music or socializing with other residents in NH environment.

QOL is indicated not only by a relatively good medical and functional health status, but also perhaps even more so by psychological and social well-being (44). Our aim was to target social and recreational programs for residents that are appropriate to their level of function and which offer them meaningful involvement in their environment.

Repeatedly researchers have reported on the health benefits resulting from social support (45, 46). In the present study, even though residents belonging to experimental group were treated for pain, it was difficult to engage them in NH`s social activities in the beginning of the intervention. An argument could be made that resident debility due to pain was the contributing factor leading to the observed inertia at the beginning of the intervention period. Certainly, debility results in decreased participatory ability and limits the array of activities that might be employed as entertainment which was clearly seen in residents of control group throughout the study, and those belonging to experimental group in the beginning of the study. The pain, illness, confusion, dementia, and the depressive symptoms are the main responses for the discouraged interactions as suggested by Schneider et al. (47). In order to encourage the interactions, we held exercise classes, focused on staff acknowledgement of residents` individuality and we emphasized on friendly and kind staff approach to residents. In the present study the social activities included homelike atmospheres, independence, reciprocity and activities that promoted interactions, in consistent with studies done by Reed-Danahay (48). We also tried to follow the intervention employed by Cohen-Mansfield (49) that involved objects or tasks with meaning specific to the person with dementia which most likely engaged the person. By the use of such interventions in the present study the participation of NH residents in social activities increased significantly in experimental group at the end of intervention. The participation in social activity was reduced from week 8 to 12 when intervention was terminated. Mean comparisons also showed that in experimental group at week 8, depression level had reduced, accompanied by increased QOL score. There is an interplay between pain, participation in social activities, depression and QOL, which could be interpreted that due to pain treatment residents` functional level increased thereby reducing depression level and increasing participation in social activities which ultimately increases QOL score. Correlation coefficient analysis showed that in control group the participation of residents in social activity was negatively correlated with depression levels. On the other hand depression level was reduced in experimental group at week 8. In consistent with study done by William and Tappen (50), we engaged patients in comprehensive exercise routine, which had beneficial effect on depression. Depression was reduced in patients with some evidence of superior

benefit from exercise; as seen by coefficient correlation analysis that participation in social activities negatively correlated with depression. Just as there are basic needs, there may also be basic social needs, that is fulfilled, yield social well-being, and ultimately enhanced QOL.

The purpose of including the blood pressure and pulse measures in this study was to provide some additional evidence, over and above a placebo effect, for the benefit of pain treatment. It was reasoned that if pain perception truly declined following the pain treatment, we should also see drops in blood pressure and pulse rate. Although blood pressure and pulse rate response to pain has been studied, no study has been published on blood pressure and pulse responses to the relief of acute and chronic pain in NH settings.

The reason that there was non-significant difference in blood pressure after the intervention could be that there may be a deficiency of endogenous opioids in chronic pain patients. In the present study at week 12 in control group blood pressure was significantly higher than experimental group at week 12 and this group was not treated for pain at all. The results indicated that the residents who reported higher pain had a higher blood pressure. It could also be a learned behavior pattern that would reduce the effect of stress.

In the present study there was non-significant difference in systolic blood pressure in experimental group at week 8, even though they were treated for pain, could also be explained on the basis of long term use of anti-inflammatory drugs, which increases blood pressure, by affecting kidney`s ability to get rid of water and salt. Other explanation for higher blood pressure could be anxiety, which is an emotional reaction, cannot be perceived cautiously and includes tension, worry and fear (51). While a general fair level of anxiety makes a person adapt to a circumstance by awaking them, an excessive and continuous anxiety can result in maladjustment by reducing one`s ability to cope with certain circumstances (52).

The pulse rate reduced non-significantly at week 8 in experimental group, but increased again non-significantly at week 12. Paired t- test showed that pulse rate increased significantly from week 8 to week 12 in experimental group. Pain increases pulse rate via autonomic nervous system stimulation and catecholamines release. At the end of intervention when the residents were with reduced pain, their depression level and skin

problems had reduced and they were evaluated for decreased pulse rate. Also regression analysis showed that pulse rate was significantly associated with QOL.

Pulse rate measurement was useful in clinical practice to indicate the presence of pain in patients unable to communicate secondary to age or cognitive impairment.

The results from the present study have clearly indicated that the pain intervention increased the QOL of patients, residing in NHs. The present study supports the conceptualization that QOL in NH residents is a process composed of many variables for example the physical, physiological and psychological, such as pain due to chronic illness and wounds, depression, blood pressure, pulse rate and socialization that interacts with one another to predict patient`s QOL. Interestingly, pulse rate that in turn depends on the pain, indirectly is the predictor of QOL along with reduced depression. Thus residents with cognitive impairments who have difficulty expressing their pain may manifest through salient outlets such as pulse rate measurements and depression.

The present study has clinical implications for maximizing QOL in NH settings where residents with cognitive impairment and chronic pain require varying levels of assistance in daily life. It suggest that chronic pain need to be routinely treated or managed in order to reduce depression and normalize pulse rate that interferes with QOL.

There are several limitations to this study. There were several patients who were taking medications for hypertensive blood pressure with possible chronotropic effects and were not excluded. The effect of specific injury, illness and fever on pulse rate, untreated to pain was also not controlled for. Another limitation is that the timing of observations centered on periods of high verbal interaction, not necessarily on when residents would likely to engage in social activities. It is possible that treatment of pain allowed residents to focus on their social environment; nevertheless, these intriguing results require further study.

Conclusion

This study is an important step in understanding how certain QOL variables are related to one another. The most interesting result of this study showed that despite residents having dementia, residents` views of their own QOL were strongly linked to their mood, in terms of

depression. The study also reports that there is an association between patient`s report of pain severity and stress- related changes in vital signs such as pulse rate. The findings suggest that treating chronic pain and painful wounds is likely to enhance the QOL indicators for overall well-being of patients residing in NH settings.

Acknowledgements

Author contributions

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Table1: Mean comparison between Control and Experimental groups with response to various variables like blood pressure systolic, blood pressure diastolic, pulse rate, skin and social activity at week 0, 8 and 12 and depression and quality of life at week 0 and 8, using Independent t-test.

Variables	Control (32)		Experimental (34)			
	Mean	SD	Mean	SD	t-value	P-value
Blood Pressure Systolic						
0 Week	138.81	20.287	134.91	31.621	0.592	0.556
8 Week	134.72	23.385	130.53	30.537	0.623	0.536
12 Week	141.41	26.499	124.18	34.906	2.248	0.028
Blood Pressure Diastolic						
0 Week	74.44	11.903	74.15	17.287	0.79	0.937
8 Week	71.63	14.372	74.38	17.423	-0.699	0.487
12 Week	72.69	15.702	73.26	19.452	-0.132	0.895
Pulse Rate						
0 Week	73.41	10.939	71.94	16.107	0.430	0.669
8 Week	71.97	11.820	69.26	19.101	0.686	0.495
12 Week	71.53	9.951	74.44	18.474	-.790	0.433
Skin Problems						
0 Week	2.38	2.420	3.82	2.68	-2,300	0,025
8 Week	3.72	2.606	0.74	0.898	6.94	0.000
12 Week	4.07	2.707	1.94	1.841	3.684	0.000
Social Activity						
0 Week	4.88	2.459	3.65	2.385	2.059	0.044
8 Week	3.31	2.292	5.21	2.24	-3.393	0.001
12 Week	2.97	2.293	3.56	2.205	-1.066	0.29
Depression						
0 Week	7.88	4.405	13.65	7.675	-3.716	0.000
8 Week	13.81	6.780	9.15	6.277	2.903	0.005
Quality of Life						
0 Week	31.94	5.913	26.44	4.894	4.124	0.000
8 Week	27.41	4.457	32.00	5.205	-3.84	0.000

If p-value is < 0.05, it is significant.

Table2a: Mean comparison at week 0, 8 and 12 for systolic and diastolic blood pressure, pulse rate, skin, social activity, depression and quality of life within control group using Paired t-test.

Variables	Mean	SD	0 vs 8	0 vs 12	8 vs 12
Blood Pressure systolic					
0 Week	138.81	20.287	1.288	-0.662	-1.636
8 Week	134.72	23.385	0.207	0.553	0.112
12 Week	141.41	26.499			
Blood Pressure Diastolic					
0 Week	74.44	11.903	1.254	0.716	-0.445
8 Week	71.63	14.372	0.219	0.479	0.659
12 week	72.69	15.702			
Pulse Rate					
0 Week	73.41	10.939	0.685	0.947	0.215
8 Week	71.97	11.82	0.498	0.351	0.831
12 Week	71.53	9.951			
Skin Problems					
0 Week	2.38	2.42	-4.816	5.003	-1.878
8 Week	3.72	2.606	0.000	0.000	0.07
12 week	4.06	2.77			
Social Activity					
0 Week	4.88	2.459	6.063	6.105	2.775
8 Week	3.31	2.292	0.000	0.000	0.7
12 Week	2.97	2.293			
Depression					
0 Week	7.88	4.405	-6.793		
8 Week	13.81	6.78	0.000		
Quality of Life					
0 Week	31.94	5.913	5.695		
8 Week	27.41	4.457	0.000		

If p-value < 0.05, it is significant.

Table 2b: Mean comparisons at week 0, 8 and 12 for systolic blood pressure, diastolic blood pressure, pulse rate, skin, social activity, depression and quality of life within experimental group by using Paired t-test.

Variables	Mean	SD	0 vs 8	0 vs 12	8 vs 12
Blood Pressure systolic					
0 Week	134.91	31.621	1.487	2.486	1.679
8 Week	130.53	30.537	0.147	0.018	0.103
12 Week	124.18	34.906			
Blood Pressure Diastolic					
0 Week	74.15	17.287	-0.117	0.339	0.52
8 Week	74.38	17.423	0.908	0.373	0.606
12 Week	73.26	19.452			
Pulse rate					
0 Week	71.94	16.107	1.583	-1.42	-2.872
8 Week	69.26	19.101	0.123	0.165	0.007
12 Week	74.44	18.474			
Skin Problems					
0 Week	3.82	2.68	6.723	5.122	-5.176
8 Week	0.74	0.898	0.000	0.000	0.000
12 Week	1.94	1.841			
Social Activity					
0 Week	3.65	2.385	-7.214	0.329	7.259
8 Week	5.21	2.24	0.000	0.744	0.000
12 Week	3.56	2.205			
Depression					
0 Week	13.65	7.675	5.761		
8 Week	9.15	6.277	0.000		
Quality of Life					
0 Week	26.44	4.894	-7.824		
8 Week	32.00	5.205	0.000		

If p-value< 0.05, it is significant.

Table 3a: Pearson product moment coefficient for inter-correlations of scores among study variables in Control Group (N=32 at week 0.

Variables	BPSO	BPDO	Pulse 0	Skin 0	SA0	DEPRO	QOL0
Blood Pressure Systolic (BPS0)	1						
Sig.(2 tailed)							
Blood Pressure Diastolic (BPD0)	.799**	1					
Sig.(2 tailed)	0,000						
Pulse Rate 0	-.438*	-0,313	1				
Sig.(2 tailed)	0,012	0,082					
Skin 0	0,343	0.412*	0,007	1			
Sig.(2 tailed)	0,055	0,019	0,968				
Social Activity 0	0,097	-0,016	-0,111	0,084	1		
Sig.(2 tailed)	0,597	0,932	0,546	0,648			
Depression 0	0,127	0,162	0,018	0,277	-0,189	1	
Sig.(2 tailed)	0,488	0,375	0,920	0,125	0,300		
Quality of Life (QOL0)	-0,316	-0,339	0,222	-0,111	-0,151	-0,161	1
Sig.(2 tailed)	0,078	0,058	0,221	0,545	0,408	0,378	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 (2-tailed).

Table3b: Pearson product moment coefficient for inter-correlations of scores among study variables in Control Group (N=32) at 8 week.

Variables	BPS8	BPD8	Pulse8	Skin8	SA8	DEPR8	QOL8
Blood pressure Systolic (BPS8)	1						
Sig.(2 tailed)							
Blood Pressure Diastolic (BPD8)	.692**	1					
Sig.(2 tailed)	0,000						
Pulse Rate 8	-0,147	0,313	1				
Sig.(2 tailed)	0,421	0,081					
Skin 8	0,263	-0,008	-0,259	1			
Sig.(2 tailed)	0,145	0,965	0,152				
Social Activity 8	0,159	-0,032	-0,195	0,015	1		
Sig.(2 tailed)	0,384	0,912	0,285	0,934			
Depression 8	-0,089	-0,098	0,006	0,006	-.391*	1	
Sig.(2 tailed)	0,628	0,595	0,972	0,974	0,027		
Quality of Life 8	-0,243	-0,222	0,057	-0462**	-0,117	-0,213	1
Sig.(2 tailed)	0,180	0,223	0,756	0,008	0,524	0,242	

**. Correlation is significant at the 0.001 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Table3c: Pearson product moment coefficient for inter-correlations of scores among study variables in Control Group (N=32) at week 12.

Variables	BPS12	BPD12	PULSE12	SKIN12	SA12
Blood Pressure Systolic (BPS12)	1				
Sig.(2 tailed)					
Blood Pressure Diastolic (BPD12)	0.739**	1			
Sig.(2 tailed)	0,000				
Pulse Rate 12	-0,154	0,074	1		
Sig.(2 tailed)	0,0399	0,688			
Skin 12	0.427*	0,213	-0.383*	1	
Sig.(2 tailed)	0,015	0,243	0,031		
Social Activity 12	-018	-0,044	0,183	-0,106	1
Sig.(2 tailed)	0,912	0,810	0,316	0,562	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table4a: Pearson product moment coefficient for inter-correlations of scores among study variables in Experimental Group (N=34) at week 0.

Parameters	BPS	BPD	PULSE	SKIN	SA	DEPR	QOL
Blood Pressure systolic (BPS)	1						
Sig.(2 tailed)							
Blood Pressure diastolic (BPD)	0.773**	1					
Sig.(2 tailed)	0.000						
Pulse rate	0.592**	0.620**	1				
Sig.(2 tailed)	0.000	0.000					
Skin problems	0.041	-0.185	0.092	1			
Sig.(2 tailed)	0.82	0.296	0.606				
Social Activity (SA)	0.029	0.236	0.102	-0.119	1		
Sig.(2 tailed)	0.873	0.178	0.566	0.502			
Depression (DEPR))	0.145	-0.05	0.166	0.228	-0.525**	1	
Sig.(2 tailed)	0.415	0.779	0.515	0.194	0.001		
Quality of Life (QOL)	0.135	0.309	0.19	-0.334	0.336	-0.470**	1
Sig.(2 tailed)	0.445	0.076	0.281	0.054	0.052	0.005	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table4b: Pearson product moment coefficient for inter-correlations of scores among study variables in Experimental Group (N=34) at week 8.

Variables	BPS8	BPD8	PULSE8	SKIN8	SA8	DEP8	QOL8
Blood Pressure Systolic (BPS8)	1						
Sig.(2 tailed)							
Diastolic Blood Pressure (BPD8)	0.759**	1					
Sig.(2 tailed)	0.000						
Pulse Rate 8	0.480**	0.605**	1				
Sig.(2 tailed)	0.004	0.000					
Skin 8	0.249	-0.404*	-0.181	1			
Sig.(2 tailed)	0.156	0.018	0.305				
Social Activity 8	0.229	0.306	0.239	-0.153	1		
Sig.(2 tailed)	0.192	0.078	0.172	0.388			
Depression 8	-0.061	0.018	0.012	0.109	-0.582**	1	
Sig.(2 tailed)	0.733	0.919	0.948	0.539	0.000		
Quality of Life (QOL 8)	0.214	0.203	0.327	-0.298	0.325	-0.438**	1
Sig.(2 tailed)	0.225	0.25	0.059	0.087	0.061	0.01	

**. Correlation is significant at the 0.001 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table4c: Pearson product moment coefficient for inter-correlations of scores among study variables in Experimental Group (N=34) at 12 week.

Variables	BPS12	BPD12	PULSE12	SKIN12	SA12
Blood Pressure Systolic (BPS12)	1				
Sig.(2 tailed)					
Blood Presure Diastolic (BPD12)	0.765**	1			
Sig.(2 tailed)	0.000				
Pulse Rate 12	0.419*	0.563**	1		
Sig.(2 tailed)	0.014	0.001			
Skin 12	0.085	-0.043	-0.007	1	
Sig.(2 tailed)	0.633	0.81	0.968		
Social Activity 12	0.003	0.245	0.287	-0.32	1
Sig.(2 tailed)	0.987	0.162	0.1	0.065	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 5a. Results from multiple scores for associations between Quality of Life and Systolic Blood Pressure, Diastolic Blood Pressure, Pulse rate, Social Activity, Depression and Skin in experimental group (N=34) at week 0. Dependent Variable: Quality of Life.

Variables	Standardized β	t	p
Blood Pressure Systolic 0	.003	.011	.991
Blood Pressure Diastolic 0	.125	.425	.674
Pulse Rate 0	.174	.837	.410
Social Activity 0	.047	.248	.806
Depression 0	-.408	-2.149	.041
Skin 0	-.228	-1.340	.191

Dependent Variable: Quality of Life at week 0

Table 5b. Results from multiple scores for associations between Quality of Life and Systolic Blood Pressure, Diastolic Blood Pressure, Pulse rate, Social Activity, Depression and Skin in experimental group (N=34) at week 8. Dependent Variable: Quality of Life.

Variables	Standardized β	t	p
Blood Pressure Systolic 8	.084	.343	.743
Blood Pressure Diastolic 8	-.154	-.524	.605
Pulse Rate 8	.344	1.746	.092
Social Activity 8	-.004	-.020	.984
Depression 8	-.411	-2.029	.052
Skin 8	-.233	-1.343	.190

Dependent Variable: Quality of Life at week 8.

Table 6. Stepwise Regression on Quality of Life with respect to Systolic Blood Pressure, Diastolic Blood Pressure, Pulse rate, Social activity and Depression as independent variables.

Model Summary

Variables	R-Square	Adjusted R-Square	F-Value	P-Value
Depression	0.192	0.166	7.587	0.010
Pulse Rate	0.302	0.257	6.711	0.004

Predictors: (Constant): Depression, Pulse rate
Dependent Variable: Quality of Life
Excluded Variables: Systolic Blood Pressure, Diastolic Blood Pressure, Skin and Social Activity.
β value for Depression Variable = -.366
β value for Pulse Rate Variable = 0.091
With Constant value = 29.075

MOBID-2 smerteskala

MOBILIZATION – OBSERVATION – BEHAVIOUR – INTENSITY – DEMENTIA

Patientens navn: _____ **Dato:** _____ **Tid:** _____ **Avdeling:** _____

Vær oppmerksom på pasientens smerteatferd relatert til muskulatur, ledd og skjelett under morgenstell. Observer pasienten før du starter mobilisering. Forklar forståelig det du vil gjøre. Led pasienten, og gjennomfør bevegelsene (1–5) med forsiktighet. Stopp bevegelsen om du observerer smerteatferd. Fyll ut skjemaet umiddelbart etter hver bevegelse:

Smerteatferd

Sett en eller flere kryss for hvert observert lyd, ansiktsuttrykk og avvergereaksjon som kan være relatert til smerte

	Smertelyder	Ansiktsuttrykk	Avvergereaksjon
	«Au!»	Grimaser	Stivner
	Stønner	Rynker pannen	Beskytter seg
	Ynker seg	Strammer munnen	Skyver fra seg
	Gisper	Lukker øynene	Holder pusten
	Skriker		Krymper seg

SETT GJERNE FLERE KRYSS I RUTEN(E) FOR DIN(E) OBSERVASJONER

1. Led til å åpne begge hender ☐ ☐ ☐ ☐

2. Led til å strekke armene mot hodet ☐ ☐ ☐ ☐

3. Led til å bøye og strekke ankler, knær og hofteledd ☐ ☐ ☐ ☐

4. Led til å snu seg i sengen til begge sider ☐ ☐ ☐ ☐

5. Led til å sette seg opp på sengekanten ☐ ☐ ☐ ☐

Smerteintensitet

Basert på observert smerteatferd; tolk styrken av smerteintensitet og sett kryss på linjen 0–10

0 er ingen smerte, 10 er verst tenkelig smerte

1. 0 1 2 3 4 5 6 7 8 9 10

2. 0 1 2 3 4 5 6 7 8 9 10

3. 0 1 2 3 4 5 6 7 8 9 10

4. 0 1 2 3 4 5 6 7 8 9 10

5. 0 1 2 3 4 5 6 7 8 9 10

Vær oppmerksom på pasientens smerteatferd som kan være relatert til indre organer, hode og hud. Smerte kan oppstå på grunn av en sykdom, sår, infeksjon eller ulykke. Inkluder all dine observasjoner fra i dag og de siste dagene (en uke).

Smerteatferd

Bruk front- og baksiden av kroppstegningen aktivt. Sett kryss for dine observasjoner relatert til smerteatferd (smertelyder, ansiktsut- trykk og avvergereaksjon)
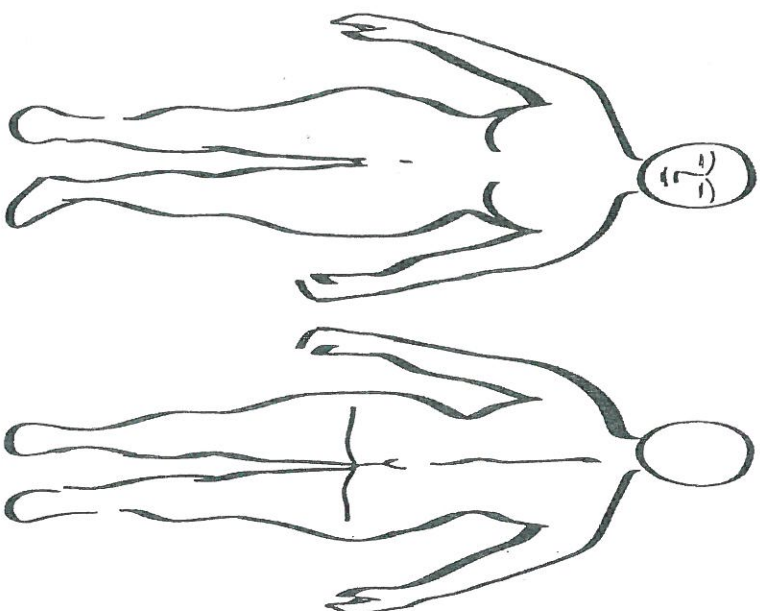
Smerteintensitet

Basert på observert smerteatferd; tolk styrken av smerteintensitet og sett kryss på linjen 0–10

0 er ingen smerte, 10 er verst tenkelig smerte

6. Hode, munn, hals

0 1 2 3 4 5 6 7 8 9 10

7. Bryst, lunge, hjerte

0 1 2 3 4 5 6 7 8 9 10

8. Mage — øvre del

0 1 2 3 4 5 6 7 8 9 10

9. Bekken, mage — nedre del

0 1 2 3 4 5 6 7 8 9 10

10. Hud, infeksjon, sår

0 1 2 3 4 5 6 7 8 9 10

Basert på alle observasjoner gi en helhetlig vurdering av pasientens smerteintensitet

0 1 2 3 4 5 6 7 8 9 10

Attachment: 2

LIVSKVALITET - QUALITY OF LIFE :   AD

Intervju - versjon for person med alders demens - Interview version for the person with dementia

Intervjuer bruker skjema i henhold til standardisert veiledning

1. Kroppslig/fysisk helse	Dårlig	Passe	Godt	Utmerket
2. Livskraft/mot	Dårlig	Passe	Godt	Utmerket
3. Sinns-stemning	Dårlig	Passe	Godt	Utmerket
4. Livs-situasjon	Dårlig	Passe	Godt	Utmerket
5. Husk/minne	Dårlig	Passe	Godt	Utmerket
6. Famlie	Dårlig	Passe	Godt	Utmerket
7. Ekteskap	Dårlig	Passe	Godt	Utmerket
8. Venner	Dårlig	Passe	Godt	Utmerket
9. Tilfredshet/selvtilfredshet	Dårlig	Passe	Godt	Utmerket
10. Evne til å gjøre oppgaver i hjemmet	Dårlig	Passe	Godt	Utmerket
11. Evne til å more seg	Dårlig	Passe	Godt	Utmerket
12. Egen økonomi	Dårlig	Passe	Godt	Utmerket
13. Livet generelt	Dårlig	Passe	Godt	Utmerket

KOMMENTARER :_____
_____

Attachment: 3

QUALITY OF LIFE : AD
Interview Version for the persons with dementia

Interviewer administer according to standard Instruction.
Circle responses.

1. Physical health	Poor	Fair	Good	Excellent
2. Energy	Poor	Fair	Good	Excellent
3. Mood	Poor	Fair	Good	Excellent
4. Living situation	Poor	Fair	Good	Excellent
5. Memory	Poor	Fair	Good	Excellent
6. Family	Poor	Fair	Good	Excellent
7. Marriage	Poor	Fair	Good	Excellent
8. Friends	Poor	Fair	Good	Excellent
9. Self as a whole	Poor	Fair	Good	Excellent
10. Ability to do chores arond the house	Poor	Fair	Good	Excellent
11. Ability to do things for fun	Poor	Fair	Good	Excellent
12. Money	Poor	Fair	Good	Excellent
13. Life as a whole	Poor	Fair	Good	Excellent

Comments :_____
_____

Attachment 4:

Author Guidelines

The editors welcome scholarly papers, addressing theoretical, empirical and methodological concerns and initiating dialogue on critical issues which contribute to the development and understanding of the caring sciences. Ethical considerations must be discussed as appropriate.

Papers are expected to have a focus on those receiving care, and a sound scientific, theoretical of philosophical base. All submissions are expected to demonstrate respect for human dignity and accountability to society.

Papers exceeding 5000 words will not usually be accepted. It is not journal policy to publish papers submitted in two parts. All manuscripts are double-blind refereed.

Papers received are assumed to have been submitted exclusively to the *Scandinavian Journal of Caring Sciences*. It is a condition of publication that authors grant the Nordic College of Caring Sciences the exclusive license to publish all articles including abstracts.

The editors will decide on the time of publication and retain the right to modify the style of a contribution; major changes will be agreed with the author(s).

Manuscripts

All manuscripts should be submitted at http://mc.manuscriptcentral.com/sics. All parts of the manuscripts must be available in an electronic format. Full instructions and support are available on the site and a user ID and password can be obtained on the first visit. Support can be contacted by phone (00 1 434 817 2040 ext. 167), e-mail (**support"scholarone.com**) or at **http://blackwellsupport.custhelp.com**. If you cannot submit online, please contact Peter Tubman in the Editorial Office by telephone 00 44 (0) 1865 476540 0r by e-mail (ptubman@wiley.com).

A covering letter must be submitted as a part of the online submission process, stating on behalf of all the authors that the work has not been published and is not being considered for publication elsewhere. A statement regarding ethical approval must also be included giving details of whether ethical approval was sought, and if relevant the name of the committee or institution which approved the study and a reference number.

The use of footnotes and appendices should be avoided.

The main text should be preceded by an abstract, not exceeding 300 words, which accurately summarizes the aims, findings and conclusions of the study. The abstract should be followed by up to 10 keywords, or short phrases for indexing purposes, which accurately identify the paper`s subject, purpose and focus.

No identifying details of the authors or their institutions must appear in the submitted manuscript. A separate title page should be submitted with author details.

Figures, illustrations, legends, tables and references should be prepared on separate sheets. The appropriate insertion points for figures and tables should be indicated in the text. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of the key aspect of the figure.

Headings within the text should conform to the following convention: upper case of main headings, lower case for major sub-headings, italics for subsidiary sub-headings. Exceptionally, a lower case, smaller font heading may be used to head sub texts, for example for case studies or vignettes within the text.

Language and Spelling should conform with that used in the *Concise Oxford Dictionary* and abbreviations with those in *Units, Symbols, and Abbreviations* (1994) published by the Royal Society of Medicine Press, 1 Wimpole Street, London, W1M 8AE. Manuscript must be written in correct English. Authors with English as a foreign language are advised to have their manuscript revised by a qualified translator or native speaker before submission.

Abbreviations should be used sparingly and only if a lengthy name or expression is repeated throughout the manuscript. When used, the abbreviated name or expression should be cited in full at first usage, followed by the accepted abbreviation in parentheses.

Quotations included appropriately within the body of the text should be marked by double inverted commas. Longer, or self-contained quotations should be preceded and followed by a double space; neither inverted commas nor italics should then be used.

Statistical methods and other methods for analysis used should be defined and, where appropriate, supported by references.

References: We recommend the use of a tool such as ENDNOTE or Reference Manager for reference management and formatting. The style of references must follow the Vancouver system and abbreviations of journal titles must conform to that of Index Medicus. Title not listed should be written in full. References with titles in languages other than English must be translated.

Examples:

1. Berglund B. Nordstrøm G. The use of the modified Norton scale in nursing home patients. *Scand J Caring Sci* 1995; 9: 165-9.
2. Savage J, Heijnen S. *Nursing in Europe: a resource for better health.* Copenhagen: WHO Regional Publications, European Series, No. 74. 1997.
3. LeGris J. Cøte FH. Collaborative partners in nursing education: a preceptorship model for BScN students. *Nursing Connections* 1987;10: 55-70
4. Van Houdenhove B, Neeri nckx E, Onghena P, Lysens R, Vertommen H. Premobid òveractive`lifestyle in chronic fatigue syndrome and FMS. *J psychosom Res* 2001; 51: 571-76.
5. UNHCR Public Information Section. UNHCR, The United Nations High Commissioner for Refugees by numbers, 2001, September, Alta Vista, http://www.unhcr

Number references consecutively in the order in which they are first mentioned in the text at which reference to a particular document is made, its number is inserted. To cite a specific part of a source (articles pages are book chapters in the reference list), indicate the page number(s) as well references should be cited from primary sources. When the book is cited, the title should be stated, followed by the publisher and town, country/state (and country if necessary) of publication.

Example: Dealey C. *The Care of Wounds: A Guide for Nurses*. 1994, Blackwell Science, Oxford.

Where the reference relates to a chapter in an edited book, details of author and editors should be given as well as publisher, place of publication, and first and last page numbers. Example: Pence G. Virtue theory. In Companions to Philosophy A Companion to Ethics (Singer P ed.), 1993 Blackwell Reference, Cambridge, 249-258.

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Attachment 5:

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Dear Sir

The enclosed report is based on a cluster randomized trial that is approved by REK-Vest and Data Inspectorate. Informed consent was obtained from all the patients before they were included in the study. This study examines the impact of individual pain treatment on the quality of life of nursing home residents with dementia in west coast of Norway. In Norway, 80% of nursing home patients have dementia and most studies have shown that there is a trend toward leaving their pain untreated which can make the patients with dementia susceptible to worsened health and thereby ultimately affecting their quality of life. However, literature review has revealed very few studies that aimed to focus on individual pain treatment and its effect on quality of life of nursing home residents. The main findings in this study revealed that pulse rate and depression level were the ultimate predictors of quality of life of nursing home residents, treated individually for pain.

I hope the manuscript will be of interest for the readers of the Scandinavian Journal of Caring Science

Yours Sincerely

Surinder Mehan

Please correspond with: Surinder Mehan, Hindalsveien 8, 4018 Stavanger Norway.

E-mail: svensen01@yahoo.no . Phone: 00 47 92663673