Review Article

Assessment and Treatment of Pain in Dementia Patients

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Abstract

Untreated or undertreated pain in dementia patients causes ineffective care and much suffering because pain identification, measurement, and management is difficult due to the different forms of dementia, other neurodegenerative processes, and the progressive worsening of verbal communication. Pain management requires continuous assessment and adjustment of treatments. There is a need for improved research and health education in the pain management of the elderly with dementia, a need for using shorter and quicker assessment scales, and for dedicating more time to understand their dementia problems to reduce the inequality of care given to them.

Keywords: Dementia, Pain, Assessment treatment, Elderly.

“There is nothing in man of a more fragile nature than memory, since it is affected by illness, injury and even fear”. Plinio, the Elder. First Century

Introduction

Pain is a common symptom in older adults under-recognized and undertreated that leads to depression, social isolation, immobility, sleep disturbance and a decrease in quality of life. It is accompanied by higher rates of hospitalization, chronic diseases, and surgery which increase their risk for pain and its prevalence vary from 40% to 80 % in nursing homes [1]. Approximately 50 % of older adults admitted to a hospital report pain, with 20 % endorsing moderate-to severe levels of pain that represents discomfort and a burden physical, psychological and social [2,3]. Cognitively impaired older adults are a particularly vulnerable population for untreated pain. The clinician caring for an elderly person with multiple comorbidities needs to consider patient preferences, the available evidence, prognosis, and clinical feasibility in deciding how to approach pain issues.

Importance of Pain

Dementia affected in 2015 to 47 million people in the world is an acquired organic mental disorder with loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning” [4].

In very early Dementia, patients maintain the ability to communicate verbally, so it is important to

1. Define the parameters of their life affected by pain and the severity of its impact
2. Comorbidities that may contribute to pain or influence its treatment
3. Identify treatment goals
4. Define the patient’s goals and preferences.

As dementia progresses, the ability to communicate verbally decreases and non-verbal communication takes over, which is more ambiguous and open to misinterpretation and more reflexive, with less cognitive control. Manifestations of pain in this group can range from behavioral disturbances such as physical aggression and lethargy to reactions of groaning and grimacing. [5,6].

Often patients’ complaints are unclear, which may be due to (a) symptom presentation, i.e., pain is confused with other complaints, including emotional distress, constipation, cold, hunger, fatigue or postural issues; (b) psychotropic medications may mask pain symptoms, and (c) caregiver attitudes and actions are also capable of altering pain detection, as they may attribute them to cognitive or psychiatric problems or tend to avoid analgesics for fear of inducing dependency or delusions. Improper pain assessment in people with impaired cognition, such as those with dementia, whose ability to report or verbalize pain is compromised, results in under-detected and untreated pain, quality of life reduction, interrupted or poor sleep patterns, impaired social interactions and reduced appetite [1-3]. Pain contributes to worsening cognition (e.g., delirium) and behavior (agitation and aggression), inappropriate prescribing (antipsychotics) and adverse drug effects (e.g., death). The high number of physical assaults on staff working in dementia wards may be related to unidentified and unmanaged pain and often results in antipsychotic medication rather than person-centered care [7]. Another reason for the current under-detection of pain is that pain diagnostic tools, classification, and assessment rely heavily on self-reports that require intact cognitive and communication skills [1-3]. Professionals need to improve their knowledge of pain assessment and management in these patients, use quicker instruments easier to use and interpret, and take more time to assess and manage pain as a team.

Assessment Pain Scales In Dementia

Patients should be assessed comprehensively before focusing on pain, starting with comorbidity and continuing with their functional capacity and dependence and the dementia itself, with inclusion of historical and background information because that helps to understand the biopsychosocial elements of pain. Fifty percent of the 47 million people with dementia worldwide experience pain [4] but this pluridimensional experience has no objective test, so the first question to be asked is “Do you have pain,” even though not all people with dementia can answer because of communication problems. When asking is important to use other descriptors of pain as aching or hurting since older patients will deny pain but acknowledge other descriptor of pain [8]. It is estimated that about 50% of elderly people in a nursing homes have cognitive impairment or mental illness and that people with a Mini Mental State of less than 15 cannot use traditional pain scales that require verbal responses. Fisher (2006) [9] and Simmons and Schnelle (2001) [10] suggested that if residents can name two objects (e.g., watch and pencil) when asked to do so in two separate tests or identify them confidently, they can provide reliable information on quality of care. For Higelman [11], the assessment of pain among individuals with dementia is complicated by overlapping observable behaviors that may indicate physical discomfort or behavioral and psychological symptoms related primarily to dementia. Pain assessment in older adults is often neglected or not done and its identification, measurement and management confront a series of difficulties due to the several forms of dementia, their different etiology, neurodegeneration process and progressive loss of verbal communication and self-report [12,13].

In all cases of real or suspected pain, a neurological and musculoskeletal assessment should be made, starting with the mouth, for its repercussions on chewing and swallowing, followed by palpation of the thoracic area, examination of spine and joint mobility in an attempt to detect trigger points, stiffness or limitations when raising the leg, bending the neck, joint mobility and deformities, as well as other autonomic, motor, and sensory changes. Hearing loss or deafness can cause confusion and disorientation and worsen isolation and are a risk factor for delirium that must be corrected [1,14]. Patients should be invited, if possible, to stand up and walk to observe their reactions, to find out if pain appears with movement, in a specific situation, and to know if it is accompanied by functional loss, inability to walk, eat, or sleep. As neither dementia nor pain is static, continuous assessment and adjustment of recommendations accordingly is advised. There are some red flags that can be indicators of serious underlying disease: cancer (history of cancer, unexplained weight loss, loss of bladder and bowel control, pain worst at night, significant sensory deficits, weakness, fractures, and infection [8].

It is necessary to know whether or not pain issues can be communicated to determine pain type — whether somatic (skin, joints, muscles), visceral, neuropathic, or mixed — its location and intensity, and its affective components and autonomic responses. For pain assessment there are several scales that may be useful in the early phase of dementia but become less valuable as it worsens, so a better picture can be obtained by adding together what the patient says, the caregiver reports, and direct observation of painful behaviors [1,14,15]. The use of scales alerts caregivers to pain and allows monitoring of treatment benefits, but ideally, any scale should give a quick measure of pain, which is important for persons in pain, who will not have the patience to choose from a list of 80 words to describe their distress. The scales should be brief (3-5 minutes) and rated on a numerical scale. Having little time for assessment and monitoring impedes correct performance [2].
In communicative patients there are valid verbal descriptive scales, visual analog scales (VAS), and numerical scales, which are generally unidimensional. The verbal scale is also descriptive but requires a choice of words to describe pain such as no pain (0), mild (1), moderate (2), severe (3) very severe (4). It is acceptable for persons with mild cognitive impairment. The foundation and focus of an observational scale is on the American Geriatric Society (AGS) (16) which presents six domains for pain assessment in older adults [16-21]. Facial expression, negative vocalization, body language, changes in activity patterns, in interpersonal interactions and mental status [16-21]. In the study by Giménez et al. (3) in Spain, facial expression (41%) followed by changes in activity patterns or routines (28%) were found to be very useful as observational tools for assessing pain behavior, as well as verbalizations (40%) vocalizations (34%), body movements, and changes in personal interactions (32%) and mental state (27%). On all scales, changes in facial expressivity and mental status are of particular interest but it may not be valid in some types of dementia in which facial expressions are muted or in conditions with distorted facial expressions, such as Parkinson’s disease or stroke [19]. (Table 1) is easy to use in clinical practice, although some of these behaviors lack specificity and may result from other symptoms or be part of a neurodegenerative process.

<table>
<thead>
<tr>
<th>Psychomotor atonia</th>
<th>Repetitive skin rashes</th>
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<tbody>
<tr>
<td>Appearance of the face: sadness, fearfulness</td>
<td>Grasping</td>
</tr>
<tr>
<td>Mouth closed with upper lip drawn up</td>
<td>Tachypnea</td>
</tr>
<tr>
<td>Frowning, frontal omega, rapid blinking</td>
<td>Sudden confusion, aggressiveness</td>
</tr>
<tr>
<td>Uncoordinated movements</td>
<td>Fists difficult to open</td>
</tr>
<tr>
<td>Moaning, grimacing, shouting, verbalization</td>
<td>Sweating of hands</td>
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<tr>
<td>Refusal to mobilize</td>
<td>Changes in mental status</td>
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<td>Hyperalgic areas when mobilized</td>
<td>Antalgic positions</td>
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<tr>
<td>Combative or disruptive behavior</td>
<td>Agitation, irritability, restlessness</td>
</tr>
<tr>
<td>Stiffness</td>
<td>Sleep disturbances</td>
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<tr>
<td>Decreased appetite</td>
<td>Tendency toward isolation</td>
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**Table 1:** Direct and indirect signs and behaviors indicating pain [21]

As one-third of those affected lose oral expressiveness as cognitive decline progresses, our ethical obligation is to measure it more frequently with the PAINAD scale (Pain Assessment in Advanced Dementia) or the DOLOPLUS 2 (a multidimensional scale for communication difficulties), and in case of doubt, to do a trial with analgesics [22] or apply the ABBEY scale. The PAINAD, (Table 2), the most commonly used scale, covers three of the six criteria of pain behaviors and measures their intensity. The patient is observed for 3-5 minutes during an activity to note breathing, negative vocalizations, facial expressions, body language, and ability to be comforted. Each item is scored from 1 to 2, with a total of 0 to 10 possible. Scores higher than 4 require intervention to control pain.
Table 2: Assessment of pain in advanced dementia PAINAD [21,22]

PACSLAC (the Pain Assessment Checklist for Seniors with Limited Ability to Communicate) assesses and tracks pain-related behavioral changes and is available at https://geriatricpain.org/pacslac. The DOLOPLUS-2 scale is based on a behavioral assessment of pain in the elderly or those with cognitive impairment. It has three domains: somatic, psychosocial, and psychomotor. A level of 5 or more indicates that pain is present (http://prc.coh.org/PainNOA/Doloplus%202_tool.pdf). Both PACSLAC and the DOLOPLUS-2 include observations and indirect signs of: (a) changes in facial expressivity, (b) verbalizations or vocalizations, (c) body movements in the form of defense, restlessness, wandering or complex stereotypes, (d) changes in activity patterns or routines affecting sleep, eating, or current habits of moving around their environment, (e) changes in interpersonal relationships: patients become irritable, aggressive, non-communicative, isolated or obstructive, (f) changes in mental state, which may take the form of confused or progressive syndromes. They are useful for detecting the presence or absence of pain, but not for its quantification. The ABBEY pain scale [23] is used in residents with advanced dementia who cannot express themselves; it is administered with the help of nurses who know them and measures the intensity of their pain. It differentiates between painful and non-painful conditions and is very valid. It is rated from 1 to 4, where a level of 3 or more indicates pain. The ABBEY scale can be completed in one minute; it has satisfactory internal consistency and distinguishes non-painful from painful situations.

Assessment of Discomfort in Dementia (Add)

Palliative care in moderate and severe dementia aims to identify all causes of suffering, including pain, provide holistic treatment with respect for person’s values and dignity, and mitigate other causes of distress, loneliness and the effects of psychotropic drugs that may mask pain. One of the basic goals of pain relief is to maximize functioning (minimize pain interference) and quality of life and minimize the effects associated with treatment. Therefore, it is essential to identify and treat the stressors that make patients vulnerable and their other medical pathologies and to reduce the undesirable effects of treatments. Dementia patients are at increased risk of infections, urinary retention, fecal impaction, pressure ulcers, fractures due to falls or surgical abdomen, and the resulting pain can contribute to behavioral symptoms (aggression, agitation, isolation, confusion) and worsen cognitive impairment. There is a protocol called Assessment of Discomfort in Dementia (ADD) [24], which is a five-element process to identify sources of physical and affective discomfort in dementia patients, as described below:

- Look for the physical causes of discomfort. If identified, seek to meet those needs, e.g., hunger, thirst, heat or cold, boredom, loneliness, sadness, loss of glasses or hearing aids, or dental pain, dysphagia, joint pain, etc.)
- Take a medical history and explore their causes of pain, noting facial expressions, behavioral expressions, mood changes with the PAINAD scale during the interview.
- If the assessment is negative for clear indicators of pain, caregivers should try to correct the altered behaviors with non-pharmacological measures (NPM), including changes in their environment. If these are unsuccessful, clinicians and caregivers should employ pain medications.

- If pain medications and NPMs do not resolve the behavioral disorder, psychototropic medications should be considered.

- If the pain persists, distraction may be helpful by focusing patients’ attention on a stimulus other than the pain or on another activity. If these signs and symptoms persist, other etiologies should be considered and a pain relief protocol initiated and responses to treatment monitored.

It is important for the clinician to try to determine whether the pain is related to distress, to pain perseveration (repeated pain referrals without emotional change), or whether it represents an unmet need or fear. Pain is in all cases an affront to human dignity, all the more so when it is avoidable in those who cannot think adequately or complain for themselves. Physical pain becomes distress when it is seen as a precursor of significant harm and may be accentuated by anxiety, stress, and the loss of other people or loved ones; clinicians should appreciate words that may signal underlying anxiety. Many patients use the words ‘worried’, ‘afraid’, ‘upset’, and ‘nervous’ for pain. Nurses can provide direct care through noticing and assessing pain, implementing a plan of care, and monitoring and evaluating effect of intervention [25,26].

**Pain and Suffering**

Chronic pain represents one of the multiple facets of suffering (physical, mental, emotional, spiritual, and social). Table 3. If pain is noted, physicians should assess whether the basic needs of these patients are being met and look for other causes of distress. Loneliness is gaining attention as a social and a health concern that affects to all ages and needs attention from all of society [27]. General practice will be important for monitoring and surveillance, as well as delivering interventions, perhaps through social prescribing. For now, perhaps the most useful contribution a health professional can make to alleviating loneliness is to have a meaningful interaction with a patient. Establishing a connection, even if only briefly, could make all the difference. Social contact, now an accepted protective factor, enhances cognitive reserve or encourages beneficial behaviors. Several studies suggest that less social contact increases the risk of dementia.

Suffering increases significantly with age, causing a serious problem for quality of life and psychosocial functioning. Suffering due to psychopathology or spiritual impairment may be expressed in a different way in dementia sufferers. Painful symptoms may present as a progression of dementia and agitation and be misinterpreted as a confused syndrome, so it is necessary to treat patients’ behavioral changes holistically and to consider that what patients describe or experience may be a manifestation of other psychological factors or a combination of physical and mental distress; for example, anxiety and depression are known to worsen pain, so it may be difficult to differentiate the origin. Many depressed patients may be very critical of past events and may be agitated, perseverative, and express feelings of hopelessness and worthlessness [21-30]. Severe pain is less likely to produce wandering and more likely to manifest in aggression and agitated behavior toward caregivers may be related to unidentified, to poorly managed pain or to perceptual problems such as hallucinations or delusions, lack of confidence in self, often results in increased rather than person-centered antipsychotic medication and has been associated with increased mortality they wake up early at night and have diurnal mood variation and suicidal ideation [31]. Another etiology to consider in this case is post-traumatic stress disorder.

| Abandonment of self, isolation and loss of meaning, loneliness | Threat of imminent destruction of the person |
| Loss of social role, abandonment | Not feeling loved, not receiving visitors |
| Inability to resolve life questions | Thoughts of guilt, fear, of future |
| Poor management of bothersome symptoms | Undesirable reactions to treatments |
| Inappropriate social situations, loneliness, lack of intimacy | Separation from family, existential suffering, fears, obsessions |
| Depression | Anxiety with cognitive and progressive changes |
| Cognitive difficulties | Progressive dependence on others |
| Family conflicts | Feeling of being a burden, a hindrance |

**Table 3:** Possible causes of suffering at the end of life [24,28,30]

**Treatment of Pain in Dementia**

Pain control is a difficult task given the multiple comorbidities and age specific factors but there are some nonpharmacological AND pharmacological therapies that will enhance pain relief and if judiciously applied, enhance the quality of life of those at the end of life [6, 31-40].

**Non-pharmacological measures (NPM).** NPM can be classified into two major groups: physical and psychosocial interventions and are appropriate for older adults particularly for those who cannot tolerate analgesics or their side effects and those at risk for polypharmacy. These have clear benefits for pain relief, behavioral changes, and quality of life and include efforts to provide direction or redirection in a non-frustrating manner, a comfortable environment, and also facilitate safe physical activity. Thus it is important to provide visual cues of acceptance while avoiding...
Older persons with impaired quality of life or function are candidates to receive analgesics which can be divided into three categories, non-opioids, opioids, and adjuvants according to the WHO Ladder, with regular rather than as-needed administration [26,28-41]. Their choice depends on pain severity, previous analgesic response, interaction with other morbid conditions, and support services [5]. Non-opioids are preferred initially, but the least toxic drugs should always be chosen before the others. Acetaminophen is effective in doses of 500-1000 mg c/4-6 h. to treat musculoskeletal pain and has a mild side-effect profile. It is prudent to use a dose lower than 2 g (in the frail) to 3 g/day to avoid hepatotoxicity. NSAIDs are useful in mild to moderate pain associated with situations such as arthritis and bone metastases. Topical diclofenac provide good analgesia to chronic knee and hip osteoarthritis. NSAIDs should not be used in high doses or beyond 2-3 weeks and should be given with omeprazole or misoprostol, which reduce but do not eliminate the risk of gastrointestinal bleeding. They can promote renal failure, hypertension, cardiovascular complications, confusion, falls, edema, and constipation.

**Opioids.** They should be used if pain is moderate or severe and to treat both acute and persistent pain in older adults that does not respond to non-opioid therapy along with continued reassessment of pain and medication effects. The benefits of treatment must always be weighed against the risk of treatment, being reasonable to give a trial of opioid therapy to selected patients especially by oral administration and to use preparations with short half-lives and no active or toxic metabolites. Other indications include the treatment of dyspnea, a reduction in diarrhea and use as an anesthetic adjunct. Volicer [22] considers that it is best to use morphine (2.5-10 mg/4h orally), with a laxative/softener combination even in people with swallowing difficulties, because it is absorbed in the buccal mucosa. It is important to start with low initial doses and increase according to response and to decrease the dose by 25% in those over 60 years of age and by 50% for those above 80 years of age, from what a 40-year old would receive [31]. It should be avoided in patients with significant renal impairment (GFR< 30 ml/min). When delayed formulations are used, short-acting formulations should be indicated for incidental pain. Many clinicians tend to avoid using opioids in dementia patients for fear that they may worsen delirium, but it appears that untreated pain is a risk factor for its development and that their use may reduce it. Undesirable effects are constipation and urinary retention, sedation, myoclonus, nausea, dizziness and mental clouding [25,31].

**Pharmacological treatment.** Acute or chronic pain and associated emotional changes that decrease patients’ attention to the environment are capable of causing neuropsychiatric symptoms and worsening cognitive impairment in severe dementia. A good working knowledge of physiological changes in the elderly, pharmacology of analgesics and good understanding of disease is required for the appropriate prescribing of analgesics to the older person [31]. It is necessary to put attention to the physiological state of the patients and drug-drug interaction because they are at special risk for prescribing cascades, which occur when a new drug is prescribed to treat symptoms arising from an unrecognized side effect of an existing therapy [31]. Pain should be assumed to be the rule as opposed to the exception and routinely assessed via expressive behavior, verbal expression, and nonverbal behavior. A randomized study by Husebo et al. [32] among 352 patients with such behavioral disorders followed a protocol of graded and progressive administration of appropriate doses of paracetamol, low-dose morphine, buprenorphine patches, pregabalin and a cathartic. After eight weeks, the intervention group with moderate to severe pain had a reduction in the severity of neuropsychiatric symptoms, with lower levels of agitation, although cognition and daily functioning were not affected and levels of agitation were similar after 12 weeks. Therefore, in the face of these neuropsychiatric reactions, a trial prescription of analgesics should be made, with low doses and progressing slowly, with a regular schedule and sufficient quantity with controls rather than increasing psychotropic medication. [31-32].
The elderly are more sensitive to the effects of opioids, so care should be taken to know if they have a reliable caregiver before prescribing them in order to minimize the risk of accidental overdose or use for other purposes by others in the home. Tramadol, should be avoided in patients with cognitive impairment due to its ability to worsen it. Buprenorphine in transdermal route as Fentanyl (12.5-25 mg/72 h) can be used in mild to moderate renal impairment and hepatic dysfunction if weight is over 50 kg. They can be used even when swallowing difficulties and produce less nausea, vomiting, and constipation than morphine. Oxycodeone (2.5-5 mg/4-6h) is another good choice because it is safer than morphine, its short half-life, no toxic metabolites and short- and long-acting forms. Patients with frequent or continuous pain may benefit from long-term medication [1]. A prospective study with long-acting, low-dose oxycodone/naloxone by Petró et al. [37], which included residents with mild to moderate dementia and chronic pain who were not using opioids, improved pain with a favorable safety and tolerability profit. Best for the use of opioids to the end of life include use of intermittent doses as needed for intermittent symptoms and a careful titration of long acting opioids [31].

Adjuvant therapy include antidepressants, anticonvulsants, muscle relaxants, and corticosteroids and are useful in neuropathic pain: postherpetic, diabetic neuropathy, metastatic bone diseases, fibromyalgia and drug-induced neuropathies. Doses should be as low as possible and increased according to response and undesirable reactions. In older patients, a trial of topical lidocaine is associated with the least side effects and should be considered the first line drug for focal neuropathic pain (painful diabetic neuropathy). Tricyclic antidepressants produce significant anticholinergic effects and gabapentin can cause drowsiness and ataxia, so pregabalin and duloxetine are more recommended. Duloxetine has been beneficial in diabetic neuropathy, fibromyalgia, chronic low back pain and knee osteoarthritis and it is well tolerated. Gabapentin may require 2-3 weeks to be effective. The combination of pregabalin or gabapentine in with duloxetine is useful in neuropathic pain [26]. In trigeminal or glossopharyngeal neuralgia, carbamazepine (CBZ) or oxcarbamazepine are the drugs of choice, while attending to the risk of hyponatremia, common in this age group with these drugs, especially CBZ; transcutaneous nerve therapy (TNS) and topical lidocaine 8% may be useful in postherpetic pain or Capsaicin injections to treat osteoarthritis-related pain in numerous joins such as the knee and shoulder, botulinum toxin in spasticity, spinal cord stimulation in failed back surgery syndrome, complex regional pain syndrome and peripheral neuropathy). Epidural injections are also used as a tool in the treatment of low back pain). Hyaluronan (hyaluronic acid) and Hyalgan (viscosupplements) are thought to work by improving the elastoviscous properties of joint synovial fluid giving relief for 13 weeks. Joint replacement is also available for older adults whose pain and quality of life have not improved with medications and non –pharmacological management. They can be effective and safe with some precautions necessary in older. Spinal cord stimulation is indicated for failed back surgery syndrome, complex regional pain syndrome and peripheral neuropathy [14,39,41].

Interventional therapies. Although many older persons can have effective treatment of their chronic pain with medications, some may develop dose-limiting adverse effects such as sedation and some fail to achieve adequate pain-relief despite being on therapeutic doses of analgesics. In these cases, joint or trigger point injections are preferable to systemic medications (steroid injections to treat osteoarthritis-related pain in numerous joins such as the knee and shoulder, botulinum toxin in spasticity, spinal cord stimulation in failed back surgery syndrome, complex regional pain syndrome and peripheral neuropathy). Epidural injections are also used as a tool in the treatment of low back pain). Hyaluronan (hyaluronic acid) and Hyalgan (viscosupplements) are thought to work by improving the elastoviscous properties of joint synovial fluid giving relief for 13 weeks. Joint replacement is also available for older adults whose pain and quality of life have not improved with medications and non –pharmacological management. They can be effective and safe with some precautions necessary in older. Spinal cord stimulation is indicated for failed back surgery syndrome, complex regional pain syndrome and peripheral neuropathy [14,39,41].

Health professionals require pain education for understanding pain assessment and management in people with dementia; improved pain assessment tools that are fast and easy to use and interpret, awareness and involvement of the teams and more time allowed for pain assessment. Many studies suggest that intensive pain management may improve the care of this vulnerable population, although the long-term benefits are not yet clear.

References


