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Pain experience and expression in patients with dementia

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Up to 2025 1.2 billion people are going to be aged 60 and more (Fine, 2009). In USA individuals aged 85 and older are the fastest growing segment of population which is expected to double until 2030 (Evers et al., 2002; Mantyselka et al., 2004). Pain is an inseparable companion of the old age. The aim of the chapter is to describe the issues of pain presence in the population of the elderly with dementia from the theoretical and clinical point of view.

We can characterize it as an unpleasant sensory and emotional sensation related to actual or potential tissue damage or described in terms of such damage (International Association for the Study of Pain, 2008). According to another definition pain is a compound, subjective phenomenon comprising nociceptive, perceptive, cognitive and emotional factors (Melzack and Wall, 1965; Cipher & Clifford, 2004). There are two main kinds of pain distinguished – acute and chronic one (Leone et al., 2009). The acute pain accounts for an essential defense mechanism which emerges in a situation of an organic or traumatic injury and its goal is to prevent the further damage increase. The chronic pain is more difficult to define because there are no clear time limits which would enable to assert when acute pain turns into chronic one. Generally it is assumed that pain, that remains longer than an expected healing time, is found to be the chronic one. Rouhgly speaking the minimum time span required for a diagnosis of chronic pain is estimated for 6 - 8 weeks (Mersky, 1986; Leone 2009) or 1 - 3 months (Sawyer et al., 2007).

Torvik et al. (2010) claims that pain is the main problem in nursery homes and an estimated frequency of its prevalence is between 27% and 84%. Similar data are quoted by Manfredi et al. (2003) who claims pain and dementia are common in nursery homes with prevalence rates of 45%-84% and 40%-78% respectively. Fries et al. (2001) reports that 68% of nursery homes residents suffers from any kind of pain. Teno et al. (2001) speaks about a range of 40% - 46% of residents experiencing pain and according to Snow's et al. (2004) estimates – 67,4%. Horgas et al. (2009) pertaining to elderly population in general states that pain is an experience shared by 50% - 86% of them.

Individuals with dementia also often suffer from pain – according to Horgas et al. (2009) this problem touches every day 32% to 53% of this group. Older research estimate prevalence of pain in the patients with dementia living in nursery homes at 60%-90% of the population (Krulewitch et al., 2000; Parmelee et al. 1993; Ferrell et al., 1990; Ferrell et al., 1995; Shega et al., 2004). There are data quoted in the literature suggesting pain prevalence in 33% to 80%

patients with dementia (Brummel-Smith et al., 2000). Shega in his research states that thirty two percent of individuals with dementia declare experiencing pain in the present moment. Among them 65% talk about slight pain, 27% about moderate and 8% about severe. Moreover, 52% of their caregivers claim that they feel some pain at the present moment, 52% talk about light pain, 30% about moderate one and 18% about severe one (Shega et al., 2004). Despite the above mentioned frightening statistics, the quoted authors in another research proved that risk of insufficient analgesia was 1.07 higher for every additional year of life, 3.0 higher if a patient suffered from dementia and 2.5 higher if a patient demonstrated impairments of activities of daily life (Shega et al., 2006). Generally, it should be stated that a level and frequency of pain prevalence in individuals with dementia are definitely underestimated (Reynolds et al., 2008; Cohen-Mansfield, 2002; Cornali et al., 2006).

What are the causes of such underestimation of pain intensity in the elderly population, especially in ones with dementia, and of insufficient counteracting it (Herr, et al., 2006)? Attitudes of the elderly, of medical staff and some research results contribute to this situation. According to Torvik et al. (2010) the elderly may reveal reluctance or not be able to complain about pain and, moreover, they may have a reduced ability to understand experienced pain and to convey this experience. Miaskowski (2000) points at more social reasons of decreased informing about pain by elderly individuals – they may meet negative attitudes of caregivers in a response to such behaviors. Furthermore, they may also assume that pain is an expected aspect of aging and due to this fact there is no reason to mention about it (Sawyer et al., 2007). Finally, lack of expected help from others may incline the elder persons to resign from complaining about it to the environment. An elderly's ability to communicate is of great importance. Sengstaken & King (1993) proved that physicians could identify pain in 43% of communicative patients and in only 17% of those who could not communicate.

Schuler et al. (2007) analyzing the causes of insufficient analgesia, which may be associated with characteristics of medical staff, states similarly to above mentioned Miaskowski, that both, personnel and residents share an opinion, that pain at the old age is a natural element of the human existence and has to be accepted because there is nothing that could be done about it. One of the consequences of such a belief is lack of sufficient attention paid to elderly's complaints on pain by nurses. Apart from it, medical staff does not have sufficient skills of pain recognition which expression may be often altered what is going to be a topic of discussion later (Zwakhalen et al., 2007). Cook et al. (1999) takes notes of too small employment of available pain assessment scales. Weissman et al. (2001; Weismann & Matson, 1999) emphasize difficulties associated with conditions prevalent at nursery homes: rare presence of physicians, shifting the burden of responsibility for direct care to not qualified enough nurses and resulting from such a situation defiance against employment of analgesics associated with a fear of administrative control.

Research results suggesting that the elderly better endure pain than the young and middleaged adults and that they declare higher quality of life, may be another source of lesser paying attention to pain in the elderly (Torvik et al., 2010). Whereas Gibson & Helmer (2001) state that age of an individual is a cause of a decreased ability to perceive pain and communicate it. Reports proving something completely opposite should be noted – e.g. Fine (2009) claims that aging can lead to pain sensitivity increase with concurrent changes in absorption, bioavailability and medications absorbing time what may only increase

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suffering. Similarly Kamel et al. (2001) states that there has been no physiological changes in the elderly found, that could influence pain perception. Indeed, people at the old age may experience more pain than younger ones (Kwentus et al., 1985) but be less prone to complain about it (Melding, 1991). With regard to this fact it should be especially kept in mind that the elderly often declare experiencing pain of less intensity than they actually feel (Ferrell et al., 1995).

Individuals with dementia are in a particularly disadvantageous situation. As Nygaard & Jarland (2005) claim, a label of dementia may distort interpretation of pain signals in patients with this disorder, what is related to lesser analgesics employment. Reynolds et al. (2008) found, that pain documentation decreased linearly with increase of a degree of cognitive impairments. Individuals without such impairments or with its mild form had higher probability of mild or severe pain recognition, while pain experienced by less cognitively efficient individuals was more often classified as mild one. Consequently, according to the authors, the higher degree of cognitive impairments, the lower probability that a patient will obtain analgesic treatment: 80% of cognitively intact residents received analgesics, while similar procedures covered only 56,2% of patient with severe impairments (P<0.001). Results obtained by Morrison & Siu (2000) approve that the problem may be an effect of communication difficulties not differences in experiencing. In the research on treatment of patients after a hip fracture – a condition independent from a level of cognitive efficiency - the authors found that individuals with dementia received one third of morphine derivatives prescribed to cognitively intact people. Brummel-Smith et al. (2002) also proved that patients with dementia were more rarely given analgesics (14% of the investigated group vs. 31% of the cognitively intact; p<0,006) and that an average time span of analgesics application was shorter (1,6 month vs. 2,9 months respectively). Moreover, Gruneir et al. (2006) also points that patients with dementia are more rarely visited by physicians and the visits times are shorter. Findings of Cohen-Mansfield & Lipson (2002) stating that cognitive status is a more important predictor of pain assessment carried out by a geriatrician than the diagnosis itself related to the pain. Furthermore, the authors note a stable trend to perceive a lower level of pain in patients with severe dementia regardless of pharmacological treatment employed to its relief.

Cook et al. (1999) mentions four causes of underestimation of pain in individuals with cognitive impairments:

- the elderly's habits associated with communicating their condition,
- a degree of acceptance of this information by medical staff,
- caregivers' skills to recognize pain,
- inadequacy of available tools for pain assessment with relation to capabilities of individuals with cognitive impairments.

It should be stated that, despite existing results suggesting that individuals with dementia can reliably communicate their pain (e.g. Parmelee et al., 1993), medical personnel does not trust relations of people under their care (Sengstaken & King, 1993). Perhaps, it is partially associated with a conviction that dementia, as a neurological disorder, may affect pain experiencing by central nervous system and cause disintegration of awareness of external painful stimuli (Reynolds et al., 2008). Moreover, other research results suggest, that more than one fifth of the elderly living in nursery homes can neither answer yes or no to a question, nor can independently communicate their condition (Ferrell et al., 1995; Parmelee et al., 1993). Marzinski (1991; Achterberg, 2007), however, claims that patients with

Alzheimer's disease show a lower level of pain than cognitively intact elderly. At this moment it is worth citing research results documenting that individuals with cognitive impairments experience similar pain as healthy controls do, and even, as it happens in case of some dementias, an increase of an affective component of the pain experience may be found (Scherder et al., 2003; Scherder et al., 2003). E.g. patients with vascular dementia may declare an increase of experienced pain (Manfredi et al., 2003; Ferrell et al., 1995). This issue is going to be discussed in a more detailed way later on.

What do we know about pain experiencing by patients with dementia? Lots of research results, especially older ones, suggest decreased ability to experience pain by this group of ill individuals. Recent reports, however, suggest that the above conviction may be rather an effect of an artifact associated with pain measurement methods. As it is underlined by some authors, most of the tools for assessment of experienced pain was developed on the basis of work with cancer patients and relies on a verbal report, what is a serious barrier in case of severe dementia (Morrison et al., 1998; Boyer et al., 2004). Bachino et al. (2001) states directly that there are no evidence proving, that individuals with dementia experience lesser pain – it seems rather that they have problem with its recognition and verbal communicating its presence. Although some researchers (Pautex et al., 2006; Stein & Ferrell, 1996; Hurley et al., 1992; Parke, 1998) suggest that individuals with dementia are able to inform about their state, more detailed studies indicate that a relationship between a number of pain complaints and a cognitive status measured with MMSE is inversely U-shaped. In initial phases of dementive process progression, the number of reports about pain experience increases, but later it starts to decrease (Merlino et al., 2002).

The topic literature is dominated by reports showing lesser prevalence of pain in population of individuals with dementia or at least higher tolerance of it. Healthy controls are compared with the ill ones, and different subtypes of dementia are compared, too. Thus, Parmelee (1996; Husebo et al., 2008) states that patients with severe dementia state less painful locations and lesser pain intensity than non-demented individuals. Leong & Nuo (2007) prove, that together with dementia progression, the amount of reported pain decreases. Similar results are obtained by Proctor & Hirdes (2001). On the other hand, other research (Scherder et al., 1999; Fisher et al., 2002; Zwakhalen et al., 2009) came to an end with a conclusion that a cognitive status does not affect pain prevalence. Blennow's et al. (1993) research results show, that cases of headache incidents as consequences of lumbar punction are scarce among patients with dementia, covering 2% of the procedure subjects, whereas in healthy elderly population they afflict about 40% of subjects. Husebo et al. (2008) compared pain experiences, their frequency and intensity in patients with different subtypes of dementia. He found that intensity of experienced pain did not differentiate the dementia groups. Instead they discovered that a number of painful locations in patients with vascular dementia (VaD) was bigger than in individuals with Alzheimer's disease. They explain it as a result of deafferentiation of VaD patients as a consequence of impairments of white matter, what is conducive to intensification of painful experiences (Scherder, Slaets & Deijen, 2003).

Researchers from the discussed domain differentiate an ability itself to experience pain and an ability to endure it. Benedetti et al. (1999; Benedetti et al., 2004) found, that patients with Alzheimer's disease have higher tolerance for pain in comparison with patients with other types of dementia and healthy elderly. These changes are visible at a neurophysiological level – an EEG pattern in patients with AD reveals an interesting relation: the slower EEG,

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the higher pain tolerance (Benedetti et al., 1999). Porter et al. (1996) and Rainero et al. (2000) proved, that autonomic nervous system responses for painful stimulation are changed in this group of patients. Namely, employing electrical stimuli was associated with both decreased perception of them and reduced increase of heart rate and blood tension. Cole et al. (2006) found that patients with AD reveal higher amplitude and latency in fMRI in response to noxious stimuli in comparison with healthy controls.

Sensory-discriminative and affective-emotional components are often discussed in the literature (Benedetti et al., 2006; Benedetti et al., 1999, 2004; Achterberg et al., 2010; Scherder et al., 2001). The first one includes perception of a painful stimulus, the second one means an emotional reaction for this perception, the aspect of suffering. The quoted authors say that in Alzheimer's disease the second component is impaired while the first one keeps stable, what results in a fact that patients with dementia can differentiate between painful and haptic stimuli (Benedetti et al., 1999; Gibson et al., 2001b; Jonsson et al., 1977). Benedetti et al. (2004) thinks, that higher pain tolerance found in patients with AD involves reduced autonomic responses what is the cause of diminished emotional processing. The authors suggest that possible anatomic underpinnings of the observed relations may be the degenerative changes within cortical centers responsible for emotions and cooperation with vegetative system, such as orbito-frontal cortex and anterior insulae (Chu et al., 1997).

According to Kunz et al. (2009a) neuropathology associated with dementia affects the pain response system after the threshold of clinical manifestation is reached – before that time it reveals its presence only at the area of the changed reactions of the autonomic system. More and more evidence confirming dysfunctions of sympathetic and parasympathetic system is found (por. Aharon-Peretz et al., 1992; Algotsson et al., 1995; Allan et al., 2007). According to the findings of Kunz and her team (2009b) changes appear before the dementia comes out, already at the stage of mild cognitive impairment (MCI). They found that patients with this diagnosis showed clear reduction of the autonomic system responses to painful stimuli. The remaining components of the pain response system were unaffected, similarly as it was in case of healthy controls. The researchers ascertained, that age and cognitive status are independent predictors of decrease of sympathetic system response for noxious stimuli. Thus, it is suggested that the neuropathological changes associated with MCI affect the pain response system in a way, that is qualitatively different from the physiological changes related to age and aging.

It should be noted, however, that decrease of response concerns only acute pain, in case of chronic pain something opposite may happen. Achterberg et al. (2007) states, that these factors in patients with dementia and suffering from disorder causing chronic pain increase probability of its occurrence. According to Bruehl and Chung (2004), it is a result of reduced activity of the efferent pain inhibition mechanisms caused by recurrent experiencing of it what bears fruit in the form of blood tension increase. Furthermore, as it is indicated by numerous research reports, the vascular risk factors such as hypertension or diabetes are strongly associated with the white matter lesions of subcortical regions (Lazarus et al., 2005; Pugh and Lipsitz, 2002; Van Dijk et al., 2004).

According to the definition, pain experience can be understood as a complex of many response components covering the cognitive and physiological aspect. Quite a popular approach is the assessment of behavior of these components in response to a painful stimulus. Relations between a subjective estimation of experienced pain, facial expression, reflexes and autonomic responses (heart rate) in a situation of experiencing pain by an individual with dementia are observed. The cognitive estimation of the pain experience by patients with Alzheimer's disease was talked over earlier. Interesting relations occur also with reference to the remaining aspects. Many authors find the increase of facial expression of individuals with dementia in response to unpleasant stimuli (Kunz et al., 2004, 2007, 2008, 2009b; Lautenbachter et al., 2007, Hadjistavropoulos et al., 2000; Porter et al., 1996). What is interesting, such intensity concerns only the pain response, it is not accompanied by general increase of facial expression. Kunz et al. (2007, 2009) is of the opinion, that it results from deficiency of an ability to control cognitive impulses by learned responses of emotions display in social situations in individuals with Alzheimer's disease. Another interpretation assumes, that it is an effect of decline of pain anticipation and situation evaluation in patients of this group (Porter et al., 1996; Benedetti et al., 2004). In the usually employed experimental set patients are provided a series of stimuli, e.g. electrical shocks. Healthy individuals adapt to the situation and in the course of time they start to predict the pain experience what bears fruit in the form of bigger control of facial expression. Patients with dementia cannot conceptualize the series aspect of the situation due to memory deficits, so every time they are surprised by a pain stimulus as if it occurred for the first time. Results obtained by Hsu et al. (2008) are in agreement with this line of reasoning. They investigated oro-facial pain responses during dentist procedures and concluded that the most useful measure for pain recognition in patients was facial expression. They regarded it especially useful in case of individuals with cognitive impairments because in comparison with healthy individuals they displayed less facial responses in anticipation of a pain stimulus, what gives evidence of lack of repeated pain occurrence expectation. What is interesting, in the past it was found that individuals with dementia show smaller emotional expressiveness due to decreased ability to feel emotions as a consequence of separation of self in these patients (Tappen i Williams, 2008).

Kunz et al. (2009a) states that dementia affects various pain components differently. Patients from the investigated group show an increased number of motor reflexes in response to pain (what in connection with increased facial expressiveness would suggest pain processing intensification) and decreased magnitude of autonomic reactions (what suggests reduced pain processing). Probably in the first case we have to do with an artifact because there are research results available that give evidence on dissociation between motor activity and pain sensations (Gracely, 2005, za: Kunz, 2009).

Pain, especially chronic pain, has a destructive influence on an older person functioning, especially the one with dementia. Being in pain leads to occurrence of cognitive (e.g. concentration difficulties) or behavioral symptoms (e.g. apathy), which, if not treated, additionally overlap on existing cognitive deficits (Cook et al., 1999). Fronidini et al. (2007) emphasize neuropsychological aspects of pain experiencing by the elderly – it intensifies short and delayed memory deficits, restricts mental flexibility and may be conducive to language impairments occurrence. In dementia pain manifestation may assume a subtle form (Husebo et al., 2009). According to Weiner et al., (1999) in case of individuals with explicit cognitive impairments such as in advanced Alzheimer's disease it comes to regression to infantile ways of self-expression because their pain, as a result of an inability to cognitively conceptualize it, loses its context. Such patients may show inadequate reactions – cry in response to a weak stimulus such as colonic distention associated with constipation (Weiner et al., 1999). Often, especially in severe dementia, it comes to development of the Behavioral and Psychological Symptoms of Dementia (BPSD; (Zanino et al., 2004; Hersch &

Falzgraf, 2007; Cipher et al., 2006; Onishi et al., 2005). Duggelby & Lander (1994) and also Lynch et al. (1998) suggest that under-treated pain may be an independent factor of delirium development. According to results obtained by the mentioned authors, uncontrolled pain, not taking opioid analgesics is a predictive factor of delirium development in the post-surgery phase.

As it was mentioned before, patients with severe dementia cannot directly communicate their pain experience due to developing deficits of communication skills. As Chibnall et al. (2005) claims pain in patients with moderate and severe dementia weakens activity and restricts engagement in interactions with environment. It may also – being a factor of behavior inhibition – be conducive to intensification of depressive symptoms, including psychomotor slowness, anergy and withdrawal. Patients, instead of complaining signal, often pain in a more subtle way, through nonverbal expression (Shega et al., 2004; Feldt, 2000) and symptoms of depression – worsening of quality of sleep, appetite decrease, withdrawal from activities of daily life (Cohen-Mansfield et al., 1990; Megni et al. 1993; Dworkin et al., 1990; Parmelee et al., 1991) or agitation (Buffum et al., 2000). In the elderly, there is a strong relationship between sensed pain and depression, stronger than in the young adults (Turk, Okifuji, Scharff, 1995). Magni et al. (1996) points to relationship between depression and pain in cognitively intact individuals – they do not find such in case of patients with dementia.

At this point, it is worth discussing an issue of agitation. Batels et al. (2003) defines it as a descriptive term employed for unspecific verbal and physical behaviors which are often met in nursery home residents with dementia. These behaviors include: wandering, motor anxiety, inadequate gestures and verbal outbursts. Prevalence rates of agitation are between 10% and 90% with an average frequency of 44,5% of nursery homes residents. Cohen-Mansfield (1989) distinguishes three subtypes of the agitation: physical aggressive, verbal and physical non-aggressive. Among them the verbal agitation is the most strongly related to pain experiencing. The physical non-aggressive behaviors are associated with better general health and smaller intensification of experienced pain (Villanueva et al., 2003).

There are doubts whether the agitation is a response to pain, especially among supporters of the view suggesting smaller pain feeling by patients with dementia. They point to a fact that intensification of agitated behaviors increases with dementia progression (Cohen-Mansfield et al., 1990), and the agitation remains despite psychotropic medication dosage (Daniel, 2000; Ballard & Burns, 2001). Manfredi et al. (2003b) proved, however, that long-term low-dose opioids treatment decreases frequency of agitation manifestations, especially in patients with dementia at the age of 85 and older.

Kovach et al. (1999) in his investigation on patients with late-stage dementia proved, that among the most often found behaviors, being a response to discomfort, are: distinct gesticulation, sad face expression, fidgeting, persevering verbalisations and verbal outbursts. Other behaviors described in the literature include (Parmalee et al., 1993; Hurley et al., 1992; Buffum et al., 2004, Manfredi et al., 2003b):

- increased agitation, repetitive movements,
- muscle tension,
- increased heart rate, blood tension and sweating,
- breathing aloud,
- facial grimace,
- aggressive behaviors

Kiely et al. (2000), among factors responsible for patients wandering, mentions: cognitive impairments (the deeper deficit, the higher risk) and experienced discomfort.

It is worth mentioning the relation between dementia intensity and behavior disorders, being a response to experienced chronic pain. Cipher et al. (2006), in his research, states that there is an explicit positive relationship between dementia severity and abnormal behaviors. Inappropriate behaviors caused by pain are more often found in patients with the severe stage than in the mild and the moderate ones. Furthermore, the behavior revealed by these individuals is more dysfunctional in comparison with the both remaining groups. Interestingly, detailed analysis proved, that a pain level does not directly affect a patient's everyday functioning. Instead it makes him/her depressed and is a cause of behavior disorders, which are a secondary source of decrease of functioning efficiency. Referring to the distinction made at the beginning of the present work, it can be said that patients with severe dementia in response to acute pain show more frequent and prolonged impulsive and aggressive behaviors that are characterized with bigger intensity than the patients with mild or moderate dementia do. On the other hand patients with severe dementia in response to chronic pain showed bigger intensity of aggressive behaviors, agitation, compulsory repetitive behaviors, delusionally motivated behaviors, wandering and inappropriate social behaviors. In case of patients with mild dementia more frequent unrealistic demands and dysfunctional behaviors have been noted.

At present, at least a dozen or so methods of assessment of pain experienced by patients is available (e.g. PASCLAC, PAINE, PAINAD, MOBID, DOLOPUS etc.). We can divide them into observational scales, basing on others' perceptions concerning a patient, and methods basing on a patient's self-report. Herr et al. (2006; Horgas et al., 2009) made a review of the fourteen scales and stated that these tools were still in an early stage of development, and required more precise psychometric elaboration before they would be able to be recommended to wider clinical employment. Similar conclusions are made by Cook et al. (1999). Most of the pain assessment tools originated on the basis of work with patients with tumour diseases, who were cognitively intact and could report their feelings and sensations (Morrison et al., 1998). Hadjistavropoulos & Craig (2002) claim, that the behavioral scales, including observational ones, measure a more automatic aspect of pain experience, whereas the methods basing on self-report engage higher cognitive centers in a greater degree. With regard to this fact, the methods of the second group may in a greater degree succumb an influence of cognitive, affective and socio-cultural factors. Unfortunately, there is no "golden standard" for the observational pain scales in dementia (Schuler et al., 2007). Then, are there no tools applicable for individuals with dementia? Fortunately, numerous research results indicate, that most of the patients from this group is able to use at least one of the available methods of experienced pain assessment (Cook et al., 1999; Cohen-Mansfield & Lipson, 2008; Zwakhalen et al., 2006; Snow et al., 2004; Scherder & Bouma, 2000). In Ferrel's et al. review (1995) the percentage of patients with dementia able to reliably use the scales, being the topic of the article, oscillated between 35% and 79%. It should be kept in mind, that a scale which is easy and simple from the point of view of a cognitively intact individual may be a very difficult for a patient with dementia. The best example of such a situation is the 100mm analogue scale ("pain thermometer"; Leong et al., 2006). Filling it is apparently easy - a subject is to mark with a cross or a point on a colorful stripe with two poles (respectively: "No pain" and "The worst possible pain") in order to assess intensity of experienced pain. However, this simple task requires an ability to interpret an abstract thought into a line, recall past states and an ability to manipulate a pencil. Because of this reason only 35% of patients with dementia can use it properly (Ferrell et al., 1995).

Generally, as it is claimed by Mozley et al. (1999), patients with dementia are not eligible for direct questioning about presently experienced pain (in a shape of a talk or employing the measurement scales) when in MMSE:

- they cannot answer correctly at least two of ten questions in the orientation dimension,
- they can answer less than three of eight items in the language functioning dimension and less than two of five in the attention dimension.

Scores on items related to memorizing and visual-constructional abilities did not affect a patient's ability to participate in the examination comprehensively.

The most popular method of pain assessment in nursery homes is basing on perceptions of caregivers – nurses, physicians or relatives. Pain assessment through observation is based on three assumptions (Villanueva et al., 2003):

- 1. Features of facial expression, posture, movements patterns may indicate presence of pain.
- 2. Pain can disrupt activities of daily life such as clothing or eating.
- 3. Caregivers can reliably observe and assess such a behavior.

Generally, with reference to physicians, it can be said that they diagnose pain reliably in patients with mild and moderate cognitive impairments, however their skills of this domain are questionable when considered with regard to patients with severe dementia (Cohen-Mansfield & Lipson, 2002). Sengstaken i King (1993) quote interesting research results – namely, they claim, that in 22% cases, pain complaints of a properly communicating patient were not noted down in a disease history. Moreover, in case of non-communicative patients, only in 17% of them, pain was noted down, what is a flagrant omission in comparison with 43% of communicative residents. Results of Snow's et al. research (2009) support a necessity of noting the information coming from a patient by a medical staff. This author found, that individuals with dementia confirming pain experiencing are at higher risk of negative psychosocial states development.

Numerous investigations on mutual relationships between caregivers' and patients' observations of experienced pain were conducted. Boyer et al. (2004) states, that, paradoxically, caregivers who are not family members present bigger convergence with a patient's opinions than his/her relatives. Similar conclusions are found in the work by Kivak et al. (1994) and Coen et al. (2002) who claim, that family members overestimate patient's functioning disorders, his/her tendency to withdraw, sleep disorders, reactivity and energy level decrease. The authors explain this tendency with a fact that these areas and disorders related to them are a source of a burden for a patient's family. As a confirmation of this way of thinking, the following finding may serve: the biggest discrepancies were between patients' and their relatives' reports, when the relative was a spouse or someone who had very frequent contacts with him/her.

At the same time, there are research results available which opt for an opposite standpoint. At least in case of employment of some of the methods such as MOBID an observer should know a patient well because then he/she obtains more valid scoring (Husebo et al., 2009). Cohen-Mansfield (2002) investigating reliability of relatives' remarks on pain experienced by patients with dementia living in nursery homes found, that their opinions were useful only when they often visited the patient. The author shows, however, the tendencies toward

biasing opinions about the patient, namely: the closer the relationship, the higher perceived level of pain; the more frequent visits, the bigger relative's inclination to observe pain and to raise its level too high. Shega et al. (2004) investigated congruence of marital diads reports about pain experienced by a patient. The authors say that higher congruence was found when a patient was male, not female. This fact can be explained with higher interpersonal sensitivity in women and associated with it skills in identifying the spouse's internal states. Reports congruence had its limits – it decreased significantly in a situation of the patient agitation occurrence.

In conclusion of the following chapter, we will think over what can be done to prevent experiencing pain by patients with dementia or at least to ease their suffering. Pain and its consequences are factors reducing quality of life (QoL) of patients with dementia. According to the definition of World Health Organization QoL is "the individuals' perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards" (World Health Organization, 1995, in: Torvik et al., 2010). Whitehouse et al. (1997) considering QoL with reference to elderly with dementia, states that it covers cognitive functioning, activities of daily life, social interactions and psychological well-being. Nagamoto et al. (1997) assuming that QoL is a moral and general feeling of well-being investigated its relations with cognitive status, depression, behavior disorders and activities of daily life. Depression proved to be the only one variable significantly correlating with QoL. The other did not show any relationships. The author suggested, that cognitive status may indirectly affect QoL because it can associate with a tendency to behavior disorders displaying. It is of particular importance, in the context of what was said before in this chapter - pain experienced by patients with dementia is conducive to occurring behavior disorders proportionately to severity of dementia and of deficits of verbal communication skills. Gonzalez-Salvador et al. (2000) in his research proved mutual correlations of the all mentioned above factors with QoL and with each other.

There are many ideas, how to improve quality of life of patients with dementia. Volicer et al. (2007) claims, that staff should provide opportunities for participation in meaningful activities, proper medical care and respond to any behavior disorders. The more versatile conception is presented by Brod et al. (1999). He distinguished five areas related to quality of life of individuals with dementia:

- 1. self-esteem (self-confidence, self-reliance, satisfaction of oneself, making own decisions, reaching own goals),
- 2. esthetics (an ability to appreciate beauty, nature and environment),
- 3. positive affect (humour, feeling of happiness, contentment and hope),
- 4. absence of negative affect (worries, frustration, depression, anxiety, sadness, loneliness, fear, irritability, nervousness, embarrassment and anger),
- 5. feeling of belonging (feeling of being loved, liked and useful).

Nursery homes staff and relatives of individuals with dementia endeavoring to ensure the highest possible quality of life should then be guided by directives defined by these five areas. It is good to join Brod's guidelines with Kovach's et al. (1999) detailed proposals aiming at improvement of comfort of patients with dementia. This author recommends undertaking the following steps:

- formalizing assessment practice from the point of view of subtle changes in a patient, which may signal experiencing physical pain or affective discomfort,
- development of nurses' assessment skills

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- more frequent employment of analgesics as a component of the assessment process which may include analgesia and dosage increase,
- teaching nursery staff about methods of non-pharmacological intervention which improve patient's comfort,
- improvement of skills of communicating results of a patient's condition assessment and negotiating, with a physician, the means of intervention which increase the patient's comfort.

Apart from the above procedures, it is important to mould pain diagnosis skills. There are various approaches to pain recognition available in the literature – some of them focus on moulding skills of specific professionals or emphasize a role of a whole team cooperation. A Hadjistavropoulos's et al. (2007) proposal is a very good example of such an approach and it is worth a closer look. The author describes settlements of the expert board according to which the diagnosis process includes three stages:

- 1. The first one includes preliminary diagnosis and monitoring of pain experienced by a patient – to reach this goal it employs the above mentioned observational scales, a patient's self-reports etc. Most of the earlier adduced considerations on pain identification in patients concerned this phase precisely. The main role is played by nursery staff and, possibly, a physician responsible for a patient.
- 2. The second stage comes out when the first one ends with a conclusion that a patient is experiencing pain. A detailed diagnosis of the patient's physical condition, employed medication and functional status is carried out (subjects of the assessment: a possibility of inflammation, sensory disorders, employed drugs, somatic concerns typical for the age, functional status, pain experienced during physical examination). It is an activity area reserved for geriatricians.
- 3. The third stage includes the assessment of psychosocial factors potentially affecting laying complaints on experienced pain. The assessment at his stage is a task for a psychologist and consists of: a diagnosis of personality, coping mechanisms, psychological well-being, affective, interpersonal and cognitive processes (general and specific) and possible disabilities caused by the pain (also: general and specific).

The above described process is a complex, long-term undertaking, but helps to avoid pitfalls leading to underestimation of pain experienced by patients with dementia and this is the reason why we definitely recommend it. A patient with dementia, especially at the late stage, is completely dependent on environment's favour, what imposes a moral duty on his/her caregivers to ensure him/her the best possible conditions at the end of his/her life. We hope that we succeeded to show in this work that pain, even if not signaled directly by patients of this group, is a common and often predominant experience of their everyday existence.

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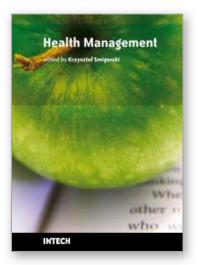
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Possibilities of medical intervention have thrived over the last decades. Our knowledge about mechanisms of the development of diseases and factors influencing it has increased. Effective treatment requires a holistic approach that takes into consideration aspects at first sight not related to a course of a specific disorder. This book contains a few chapters focusing on issues related to health management. The chapters are arranged in an order reflecting multidimensionality of issues constituting this theoretical and practical area - starting from the studies focusing on a general, administrative level, to considerations related to situations of individuals suffering from a specific illness. The discussed problems concern different age groups - children, adults and the elderly. We hope that readers professionally engaged in healthcare - both theoretically and clinically - will find it interesting, useful and inspiring.

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