Pain *in* Dementia

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Wolters Kluwer

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DEDICATION

For those, who lost their voice to speak for themselves, and for those, who try to speak for these but often do not exactly know what to say. They all were reason for writing and editing this book and deserve our gratitude for their inspiration. May this book be a little help for them!

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PREFACE

PAIN IN DEMENTIA: A DISTRESSING DOUBLE BURDEN ON MANY

Dementia has been called "the 21st century plague". There are many millions of people suffering from dementia worldwide and the number continues to rise. Up to 80% of people with dementia living in care homes regularly experience pain. Pain in dementia is usually related to musculoskeletal, gastrointestinal and cardiac conditions, genitourinary infections, pressure ulcers, and oral pain. Neuropathic pain, defined as pain caused by a lesion or dysfunction in the central nervous system, is common in dementia. Despite these numerous established causes of pain, international epidemiological research has reported that the use of pain medication is often inappropriate in this patient group. Consequences of untreated pain include mental and physical impairment, a higher frequency of neuropsychiatric symptoms such as agitation, depression and sleep problems, and adverse events like falls, hallucination, and even death.

Thorough assessment of pain is essential to ensure effective treatment and ongoing care. In most patient groups, the most effective method of identifying pain is through self-report. However, a key symptom of dementia is the loss of ability to communicate, particularly in the later stages of the condition, largely allowing only observers to identify and rate the pain. A further major problem in assessing pain in dementia is the difficulty to distinguish pain from other behavioral symptoms that commonly arise in people with dementia. The inaccuracy in diagnosis can in turn result in inappropriate treatment, even including the use of antipsychotic medications instead of analgesics. Treatment approaches are further hindered by a neglect of nonpharmacological options, too few multidisciplinary and palliative care programs, as well as an insufficient integration of treatment and care.

To overcome this distressing situation for patients, relatives, and societies, basic and applied research, which provide better diagnostic tools and treatment strategies, as well as education of a new generation of experts are urgently needed. As with many aspects of dementia research, the critical relevance of the troublesome combination of pain and dementia was overlooked until the latter part of the last century. **The present book is an attempt to stress the relevance of these topics and delineate the state of the art in the search for solutions.** A short outline of the book should give some evidence for the seriousness and comprehensiveness of this attempt.

- **Preserving the dignity** of those suffering both from pain and dementia is a major obligation for all being active in research, care, and treatment and should therefore be the ethical guideline for all our scientific and clinical considerations *(Chapter 1).*
- **Basic knowledge and facts about pain in dementia** are always necessary as the basis for deeper understanding and scientific as well as clinical applications. Therefore, the nature of dementia *(Chapter 2)*, the specific characteristics *(Chapter 3)*, and the prevalence *(Chapter 4)* of pain in dementia are implemented as contents in the book.
- The **neurophysiological interaction between dementia and pain** is described from the perspective of neuroimaging *(Chapter 5)* as well as from the perspective of neuropathology and neuropsychology *(Chapter 6).*
- The **neuropsychiatric consequences of pain in dementia** sometimes mask the classical symptoms of pain and therefore deserve extra attention *(Chapter 7).*

- In **other forms of cognitive impairment** (e.g., mental retardation), similar problems regarding pain assessment and treatment may arise, making mutual exchanges of experience and knowledge between domains worthwhile *(Chapter 8).*
- The proper **assessment of pain and associated problems of pain in dementia** is a scientific milestone of finding clinical solutions for this major health problem and requires various approaches, namely using self-report measures of pain *(Chapter 9)*, applying instruments for observer ratings *(Chapter 10)*, detailing analysis by psychophysical and behavioral tools of assessment *(Chapter 11)*, considering not only pain in general but also specific forms like orofacial pain *(Chapter 12)*, integrating the use of various instruments into informative guidelines *(Chapter 13)*, and finally widening the scope by seeing the pain-associated problems leading to mood and emotional disturbances *(Chapter 14)*, and cognitive *(Chapter 15)* and functional *(Chapter 16)* impairments.
- The **care and management of pain in dementia** are necessarily multidisciplinary and multiprofessional, including approaches developed by caregivers and academic nurses *(Chapter 17)*, pharmacological strategies of treatment *(Chapter 18)*, treatment attempts contributed by physiotherapists, ergotherapists, and others engaged in physical activity–related therapies *(Chapter 19)*, or by psychologists and psychotherapists *(Chapter 20)*. The proponents of all these therapeutic attempts have to bear in mind that the mind of patients with dementia can no longer heal as good as before and placebo action is reduced *(Chapter 21)*.
- **Special challenges and conditions of pain management in dementia** are given on the one hand when the complexity of caring and managing patients with both pain and dementia is further enhanced as soon as patients enter the end-of-life phase *(Chapter 22)* and may be unburdened when the potentially active treatments just mentioned are combined in multidisciplinary programs for the easy participation of aged patients with dementia *(Chapter 23)*.
- **Special ethical considerations** are necessary when patients with dementia become participants in clinical research and treatment trials *(Chapter 24)*.
- Cross-**cultural thinking** is required to see the stability and variability of the problem of pain in dementia across different societal settings *(Chapter 25)*.
- Whether **research on nonhuman animals** can improve our understanding of pain in dementia and may help to avoid frail patients being study subjects is worth discussing *(Chapter 26)*.
- A few thoughts about **future directions of research and clinical practice** regarding pain in dementia may round up the accumulation of facts and theories in the book *(Chapter 27)*.

We cordially thank the International Association for the Study of Pain (IASP), IASP Press, and Wolters Kluwer for their support in making this book with such a wide and comprehensive scope, which allows us to consider all relevant aspects of this pressing topic. We also thank our authors for their outstanding contributions.

Pain in dementia will unfortunately remain a problem for many more decades. We hope that this book may add a bit to the multidisciplinary and international approaches to educate clinicians, researchers, and caregivers in the presence and to form a new generation of experts better prepared to look for new scientific and clinical solutions as well as to inform a best-possible practice for the future.

Stefan Lautenbacher and Stephen J. Gibson
November 2016

CONTENTS

CHAPTER 1

The Concept of Dignity, Suffering, and Pain in Frail Old Patients and Persons with Dementia

Stein B. Husebø and Bettina S. Husebø

> "A medical revolution has extended the lives of our elder citizens without providing the dignity and security those later years deserve."
>
> (John F. Kennedy, 1960)

In most developed countries most of the population will reach an age of 80 years or more. In their final frail years before death, they will increasingly need support of care services, and be more or less dependent on others. What are their needs? How can we establish and provide optimal care, security, pain, and symptom assessment and management? How can we identify and relieve suffering? How can we respect their dignity and relieve their suffering and pain in their final years before death [23]? This chapter will discuss the concepts and practical challenges of dignity, suffering and pain, both for the multiprofessional team, and for the frail old and their next of kin.

DIGNITY

United Nations Universal Declaration of Human Rights 1948 stated, "All human beings are born free and equal in dignity and rights," (www.humanrights.com). We also find the concept of and duty to protect dignity implemented in the basic laws and judicial decisions in many legal systems, as well as in international covenants and declarations on human rights. But no country has gone so far as Germany in integrating dignity in its legal system. As stated in the first sentences of the Basic Law (Grundgesetz, www.bundestag.de), the inviolable dignity of human being is a fundamental constitutional principle: "Human dignity is inviolable. To respect it and protect it is the duty of all state power. The German people therefore acknowledge inviolable and inalienable human rights as the basic of every community, of peace and justice of the world [27]." But, what is the meaning and content of dignity? Dignity as an idea has a long and important history in ethics, not denoted to a single essence. A central statement to dignity comes from Immanuel Kant, "In the kingdom of ends everything has either a price or a dignity. What has a price can be replaced by something equivalent; what on the other side is raised above all prices and therefore admits of no equivalent, has a dignity [35]."

Human dignity is complex, ambiguous, and multivalent, challenging us to look at the use of ideas in order to probe the depth of their meaning. On the one side all human beings have their inviolable, intrinsic dignity. On the other side their dignity can be violated or confirmed by others. Moody argues for the need to address, discuss, and understand basic words, specific ideas, and challenges of dignity in each specific patient, such as [27] follows:

Self-respect	vs.	Shame
Honor	vs.	Humiliation
Decorum	vs.	Inappropriate behavior
Privacy	vs.	Exposure
Power	vs.	Vulnerability
Equality	vs.	Favoritism
Adulthood	vs.	Infantilization
Ego integrity	vs.	Despair
Individuation	vs.	Objectification
Autonomy	vs.	Dependency

Whether by stroke, by dementia, by other severe or chronic disease, by loss of close relatives, by poverty, or by pain, we stand at risk of losing everything achieved over a lifetime. Each of us, however, dimly, carries this unspoken awareness during our lives. Life can end badly, filled with pain and suffering; fear of aging is rooted in this understanding.

Dignity in old age matters because every one of us carries this sense of future vulnerability and because we fear becoming dependent burdens to ourselves and others in our last stages of life. Contemporary debates about euthanasia, concern over mistreatment of the frail elderly, anxiety for isolation, pain and suffering, all revolve around a primal fare: loss of dignity in old age [10, 34].

Pain, suffering, and dignity are closely linked to each other, demonstrated by the research and publications of the psychologist H. Chochinov who provides practical guidelines for "dignity therapy" in end-of-life care, primarily with focus on cancer patients [5]. Recently, his model was tested on older persons in nursing homes [12, 13], also on patients with cognitive impairment [6], providing courage for practical dignity interventions in long-term care.

DIGNITY—WITH LACK OF AUTONOMY

Most philosophers connect dignity with autonomy. Max Frisch (1911–1991) probably has the shortest version: "Dignity means the freedom to choose" [11].

Among publications with regard to quality in long-term care, one of the earliest, Home Life introduces the principles of care as "Residents have a fundamental right to self-determination and individuality"—that is autonomy [4]. Although, most centers for elderly care have procedures in place to exercise choice, on information, or services provided and how to complain, only a few provide the opportunities to comment on policy and procedures, planned changes, and suggested treatment and care [2]. This is even more concerning in patients with dementia or without a supportive relative.

For the large and rapidly increasing number of patients with dementia, there will be a decline of autonomy. Their dependency on the choices of others will increase. Their ability to self-report diminishes. They lose ability to claim their human rights. They still have their basic, intrinsic dignity, but now dependent on the respectful and wise choices of care givers, based on their insight, attitude, and competence. Our approach caring for these patients with lack of autonomy must have main focus on "seeing" the individual with his/her biography and life project: which goals, preferences, and decisions will the patient have, and would have had, for the rest of their life? Respecting dignity, All care givers should be aware of the patient's biography, also including the patient's life project: which goals, preferences, and decisions will the patient have, and would have had, for the rest of their life?

A nurse's statement illustrates how vulnerable dignity and autonomy at old age can be: "If I suffer from dementia, no longer able to make competent decisions and somebody remove my breast holder, without reflection if I would have liked my breast holder to be removed, I would kill them. . ."

Nora, 92 years old, patient in our nursing home, expressed her view on dignity: "Well, they give me a pill to stop me from crying, because my husband died. . ."

The appeal to dignity, more strongly the insistent claim to dignity, points to something in us which is genuinely transcendent, something which reflects our freedom to call into question all social roles, to say out loud that I am something more than my frailty or my role performances or my buying power. At that moment, the passive witness rises up to say, "You can't treat me that way." The moment we speak these words, dialogue becomes possible and advocacy becomes inevitable. The outcome of this struggle is never certain, but this struggle for dignity emerges again and again through the course of history. It is a cry for justice as much as an affirmation of meaning.

SUFFERING

In a remarkable article in *New England Journal of Medicine* 1982, Cassell [3] discusses the question of suffering and its relation to organic illness, which has rarely been addressed in the medical literature before. His article offers a description of the nature and causes of suffering in patients undergoing medical treatment. A distinction based on clinical observations is made between suffering and physical distress. "Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself."

THE CONCEPT OF PAIN

The concept of pain also needs to be addressed. In IASP (International Association for Study of Pain, www.iasp-pain.org) taxonomy, we find the following definition:

"Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."

Merskey and Bodguk [25] note that "the inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience. Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. There is usually no way to distinguish their experience from that due to tissue damage if we take the subjective report. If they regard their experience as pain, and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain. This definition avoids tying pain to the stimulus. Activity induced in the nociceptor and a nociceptive pathway by a noxious stimulus is not pain, which is always a psychological state, even though we may well appreciate that pain most often has a proximate physical cause." Interestingly, in most articles, lectures, and clinical settings on pain, only the first part of this definition is presented and addressed, overlooking the very important included "Notes on Usage" as the second part, concluding with "Activity induced in the nociceptor and a nociceptive pathway by a noxious stimulus is not pain, which is always a psychological state."

Biologists like to tie pain to a bodily stimulus, then loosing that pain always is a psychological state experienced by persons. It is important to include reference to Cicelys Saunders' (the founder of palliative care) term "total pain" since it nicely encapsulates the foundational concept underlying all suffering and that is that all human experience is modified by the status of the whole person in each domain. The first reference for it appears to be in her paper "The Last Frontier" by Saunders [31]. In it, she quotes a patient describing her pain, "It began in my back, but now it seems that all of me is wrong." Cicely Saunders then explains, "This kind of 'total pain' has physical, mental, social and spiritual elements. Neither the patient in her words nor we in our approach and treatment can deal with any of these separately."

When persons state, "I suffer," or "I am in pain," we need to accept their statement. Our next task is to reflect on and analyze their statements, asking the questions: What do they express? What does that mean, for them, and for me? Is it a warning signal? Fracture of a hip, toothache, appendicitis, or cancer disease? My husband left me? I am depressed? I feel lonely?

Before we eagerly start with interventions, operations, analgesics, or exercise, we need to assess the details. But first of all we must read the patient's pain concept as a whole. Examinations, self-rapport, and systematic observation of behavior provide important information. In many situations in life, to listen with patience, to provide a plaster, and to provide a good explanation or rest will relieve the suffering and pain, depending on the underlying cause.

ADVANCE CARE PLANNING

Another central key to optimal treatment and care and end-of-life care is open, preparing communication, Advance Care Planning (ACP) with patient and relatives, addressing the closer-coming death and the practical challenges regarding ethics, site and quality of stay and care in good time before the situation and symptoms develops [8, 26].

The physician must take the initiative and role as conductor in this process. Without the physician, the communication will develop huge and unnecessary gaps and remain fragmental. The key questions all physicians caring for frail, dependent old patients with multimorbidity or dementia must consider are "How long the time frame my patient has left? Will she be alive in 6–12 months?" [24]. If the answer to the last question is no, he or she should take initiative to meetings with the patient (if possible), the relatives, and caring staff. Central issues should be addressed and discussed, for example, the physician's considerations regarding health, illness, treatment options, side effects and limitations, time perspective, goals, pain and symptom assessment and treatment, and palliative care.

A special attention should be on ethical questions like informed consent, presumed consent and advance directives, the written ethical decisions at the end of life. The physician's statements should be reflective and clear, especially regarding who is responsible for what, and invite to questions and discussion. A summary of the meeting must be documented in the patients chart and available for all. In the next weeks and months, follow-up meetings should be planned and organized, especially when life-threatening complications occur.

Patients suffering from progressing dementia represent a special challenge due to cognitive failure in their last years increasingly will lose their ability to understand and make qualified statements and choices. The optimal goal must be to openly discuss and document the developing of the disease, ethical and practical challenges with them and their relatives before cognitive failure becomes a problem.

"IS THERE HOPE, DOCTOR?"

The physician's hope is often connected to survival. Comments such as "My task as physician is to fight for survival and to support the patient hopes" are common [16].

The professionals in the health services have an education and focus on prevention and cure of illness, goals shared by the patients and their relatives. The central target of medical interventions is mainly to identify and treat diseases. As long as these goals of restoring health or prolonging life with quality seem reachable, we all will fight for this hope of more time of life, and accept all burdens of treatments side effects.

But earlier or later all of us, especially the frail old, reach a point where there no longer is hope of curation or a prolonged life with quality. This "point of no return" must be identified and communicated. It should be a "point of establishing maximal attention," a time for fundamental shift with new therapeutic and caring goals, now with main focus on all perspectives of palliative care [17–20].

Many physicians find this fundamental shift difficult [24]. Some hardly recognize its existence. But the disease-focused model often becomes a burden for dying old patients [15]. To focus on survival or life-prolonging interventions can destroy their hope. Their hope at end of life is huge, now connected to openness, preparing communication, pain and symptom relief, relations, meaning, grief, love, attitude, and farewell.

The largest violation of a dying person's dignity and hope we can imagine is that they in their last days and hours of life are transported and referred between home, nursing homes, emergency wards, hospital or intensive care units, without the necessary, open, preparatory communication that a human being is dying, and that time has come for farewell.

PATIENTS WITH COGNITIVE FAILURE

Oddvar was 82 years old. After a serious stroke, his vascular dementia was diagnosed 4 years ago. He had been in the nursing home the last 6 months. His cognitive failure was moderate with mini-mental-state examination score of 18. He did not complain or report on pain. Due to his degenerative arthritis he received acetaminophen 3 g daily. Benefit in mobility and activities of daily living were observed. Despite some improvements in his