A Draft for an Integral Concept of Dementia

Translation of my Masterthesis in Gerontology (M.Sc.) at the University of Erlangen, 2011
"Entwurf für ein integrales Demenz-Konzept"

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Foreword 2024

The project to translate the Master's thesis into English took many years to realize. In the meantime, my understanding of dementia has changed and broadened considerably, which is normal for a scientist's cognitive process. So today I can see the limitations and also the mistakes in my work at the time and can still appreciate it as a unique part of my thinking at the time. At the same time, I can recognize that this work triggered an expansion of my consciousness at the time; I still remember that when I was thinking about the autopoiesis of dementia using the example of apoptosis (ch. 5.2.3), I thought "my head is breaking"; I now know that this gave me a perspective that really had to break my previous thinking, my previous "head", because otherwise I would not have been able to grasp it and integrate it into my thinking.

I have corrected a few errors in the translation and made some minor cuts for linguistic reasons - so it is not a completely word-for-word translation, but it is very close to the original.

Foreword 2011

The fact that my academic studies have been completed and that this work lies before me is not something to be taken for granted, and there are many people who have accompanied me on this journey. I would like to thank them all:

Sabine Engel, Professor of Psychogerontology at the University of Erlangen, for her willingness to accept this topic as a Master's thesis, for the great interest with which she followed and accompanied the development process and especially for her trust in me and my research project.

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This thesis is the culmination of a part-time postgraduate course, and I was able to count on the support of two people to help me complete it: Peter Smolka for his generous hospitality in Erlangen, and Christian Fleck for helping Florian cope with the upheavals my studies brought him.

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Note: Most of the German thesis was translated with Deepl Pro and proofread afterwards. I have read Ken Wilber in German, I apologize for imprecise translations of certain integral terms into English. All German citations are translated with deepl.com from the original if not mentioned otherwise. The English citations should now be all original. Please note also, that this is a corected version of the master thesis in that sense, that I corrected or adjusted all quotations with errors, which I have to confess that I have found some in the original, when I was looking up the original English citations.

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1 Introduction

The medical perception of dementia as a disease or disorder is still prevalent, not only in the medical literature (Förstl, 2009a; Mahlberg & Gutzmann, 2009a), but also in politics (BMFSFJ, n.d.) and advocacy groups (Deutsche Alzheimer Gesellschaft, 2008). Public opinion is also influenced by this view, as the media frequently show a medically dominated understanding of dementia, as it can be seen from ramble through the online portals of well-known magazines such as Stern or Spiegel or even daily newspapers from the Frankfurter Allgemeine Zeitung to Bild. Television magazines also do not dispense with 'medical expertise' when they have dementia as a topic (Quarks & Co, 2010).

But there are also new approaches to dementia, such as by Peter Whitehouse (Whitehouse & George, 2009), who, as a former authoritative scientist in pharmacological dementia research, 'debunks' the myth of Alzheimer's and contrasts his model of brain aging with the medical concept of dementia as a disease. Richard Taylor, a person affected by dementia, has also contributed to changing the image of dementia with his autobiographical publication Alzheimer's and I, and his provocative thesis therein "There is no such thing as Alzheimer's disease!" (Taylor, 2008, 36).

In Germany, two congresses resp. conferences on dementia in 2010 have shown that the image of 'dementia' is currently in a process of change. At the Dementia Fair Congress in April 2010 in Nuremberg, Helga Rohra, member of the board of the Alzheimer Society Munich and a person with dementia, was still accused of lying by a medical doctor during her presentation about her experiences with the diagnosis and the way into the public eye, because in his opinion she could not be affected by dementia due to her ability to articulate. At the open conference of the German Ethics Council on the topic of *Dementia - End of Self-Determination?* in Hamburg in November 2010, Helga Rohra could again be seen taking part in the concluding panel discussion with representatives from science and politics as a partner in conversation as a matter of course (Deutscher Ethikrat, 2010). If one takes these two events together from the perspective of the congress and conference visitor, then within a few months a change took place in the acceptance of Mrs. Rohra as a 'competent person' from a person affected by dementia who was not accepted by the scientific community to an interlocutor who was included as a matter of course by the scientific community.

The image of dementia seems to be in a gradual change, at least according to the facts reported here. But one question remains unanswered: What is dementia? For even if public and scientific attention is slowly opening up to a changed picture of dementia, the medical supremacy of definition does not seem to have changed much yet, as Wetzstein (2005a), Whitehouse and George (2009), and Wißmann and Gronemeyer (2008) show. Can

dementia continue to be defined as a disorder when affected persons and scientists discuss it at the same table?

The above examples are meant to be representative of a variety of perspectives, opinions, and sometimes controversial viewpoints in the current discussion of the question: what is dementia? So far, there is no model, no theory, no concept that can provide an answer that all individuals and groups involved can agree upon. There is also no model that is comprehensive enough in its scope to combine the different scientific findings and professional as well as personal positions and to bring them together in one explanatory approach.

Integral Theory according to Ken Wilber (1997, 2000a) claims to be all of these: comprehensive, unifying, and bringing together seemingly conflicting positions. As a theory of consciousness that builds on the work of numerous theorists in philosophy and consciousness research (McIntosh, 2007; Wilber, 2000), and which is shown to be a multidimensional model in its structure (Wilber, 1997), it lends itself as a theoretical basis for bringing together the various concepts, models, and opinions on dementia with the goal of an overarching, comprehensive concept of dementia that does not seem to exist in this form to date.

This thesis pursues the epistemological claim to develop a draft for an integral dementia concept based on Integral Theory, with which the phenomenon of dementia can be represented in its manifold relations in such a way that as many as possible of the hitherto seemingly contrary positions on dementia can be included. It will be examined to what extent a synthesis of dementia and Integral Theory can be realized and meaningful, and to what extent Integral Theory is suitable to represent the phenomenon of dementia in the most comprehensive way possible.

Chapter 2 provides an introduction to the current state of research on definitions and concepts of dementia under the question "What is dementia? Chapter 3 provides an introduction to Integral Theory, with a brief overview of its history, (scientific) reception, and theoretical background. An overview of the structural elements and the Integral Methodological Pluralism as a basis for the further procedure in this thesis will follow. Chapter 4 sets up the premises for the subsequent epistemological elaboration of the basic structures of an integral dementia concept by describing in detail the object of research, terminology, and approach. Chapter 5 examines whether it is possible to describe dementia in its multidimensionality with the help of Integral Theory as an epistemological guide and thus to develop a draft for an integral dementia concept. Chapter 6 reviews the results of the previous chapter by means of a literature analysis. The results are discussed in Chapter 7 with regard to the extent to which the Integral Theory appears suitable as a basis for a dementia concept. Furthermore, the theoretical approach of this work will be briefly reflected on and concluded with an outlook on possible further research.

Finally, two clarifications of terms are necessary:

The persons, who are in the center of the consideration of scientific research around dementia, are called in this work people with dementia (Wißmann & Gronemeyer, 2008) or "the person affected" or "affected person". [Unfortunately, there is no appropriate English translation for the German word "Betroffener".] The term affected person originates from the field of social work and refers to people who usually find the occasion that makes them an affected person unpleasant (de:Wikipedia, Betroffene). Nevertheless, the use of the term remains imprecise, because also the relatives of people with dementia often perceive their situation as unpleasant (Engel, 2008) and are therefore 'affected'. For this reason, a more precise definition is necessary: In this paper, the term affected is used exclusively for the group of people with dementia.

Another preliminary remark seems necessary for the use of Wikipedia: In this work Wikipedia is used as an encyclopedic source of information. In science, there are reservations about the scientific relevance and quality of Wikipedia articles (cf. among others Nentwich, 2009; König, 2009), so the point of view and procedure for dealing with Wikipedia sources will be briefly explained here.

Wikipedia is defined as an encyclopedic project via its own guidelines (de:Wikipedia, Wikipedia). It is thus not scientific literature, but as an encyclopedia it reflects the state of scientific positions. Numerous scientists and scholars contribute to Wikipedia articles, and the quality of the articles is high in many areas (König, 2009). However, the articles can also have obvious or subtle quality deficiencies (König, 2009; Weber, 2005), so a personal quality check of the articles is advised before using them in a scientific context.

In this work, articles of the German or English Wikipedia are consulted, which are characterized by a professional discussion of the content (on the discussion culture as a quality feature, see Haber in Staas, 2010) as well as do not contain any quality assurance entries at the time of the call (see de:Wikipedia, Enzyklopädie/Qualitätssicherung in der Wikipedia). Furthermore, Wikipedia articles are predominantly used to define terms and to present a current state of discussion.

Since there are no clear guidelines for the citation of Wikipedia, the following procedure is chosen: The complete article name without year is given after 'Wikipedia', in the list of sources after 'Wikipedia. Artikelame' the date of the used article version is mentioned. In this way, the information content used can be traced on the basis of the version history of an article, also after long periods of time.

2 State of research on definitions and concepts of dementia

Many textbooks on dementia start with the basic medical facts about the development and course of a so-called dementia-related disease, which are accepted as valid by a large part of the scientific community (e.g., Förstl, 2009a; Mahlberg & Gutzmann, 2009a). Data on prevalence and incidence open up various professional articles on dementia, e.g. on prevention (Laske, 2007), nursing care concepts (Nocon, Roll & Schwarzbach et al., 2010) or on exercise programs for people with dementia (ProAlter, 2011). Information about forms of dementia, about current and future costs of care for people with dementia, about risk potentials and prevention possibilities can be found regularly in many media; searches on the online portals of Spiegel, Stern and Focus, but also of Bild [some popular German magazines and newspapers], yield a high number of articles on dementia. All sources have in common that details are reported extensively, but rarely the question is answered: What is dementia actually, what is this phenomenon that has broken into the health care system, the media and above all into the everyday life of so many people in such a dominant way? This chapter provides a brief overview of current answers to this question.

The primary interest of this work is not the much-cited details. Rather, it is an attempt to gain an overview of dementia in its entirety. It will be attempted to describe and capture dementia in as many facets of its appearance as possible. This also includes details such as epidemiology, symptomatology and therapy, but they are ultimately only of minor interest with regard to a comprehensive overall picture of dementia in its possibly much broader references up to legal sciences, literary research, urban planning and architectural aspects and much more. Therefore, for the time being, reference is made to the relevant literature for the general data on dementia (Förstl, 2009a; Kastner & Löbach, 2007; Kieckebusch, 2010; Mahlberg & Gutzmann, 2009a). Where necessary in the context of this thesis, the relevant data will be referred to later.

The question "What is dementia?" cannot be answered with a simple, universally valid formulation. Nevertheless, it is a question that concerns almost all persons involved in the phenomenon of dementia: What is dementia? How can this phenomenon be described, explained, researched and perhaps even eliminated? What is it? A disease? Or is it rather a normal phenomenon of old age (Plemper, 2010; Whitehouse & George, 2009)? In recent years, more and more voices have been raised calling attention to the increasing demonization of the alleged disease dementia and the one-sided occupation of the interpretive authority over this phenomenon by the medical experts (Dammann & Gronemeyer, 2009; Wetzstein, 2005a; Whitehouse & George, 2009; Wißmann & Gronemeyer, 2008).

The current state of research on the aforementioned questions is approached from two directions in the following: First, the current state of definitions of dementia is considered in order to gain an overview of how the question "What is dementia?" is answered in current scientific, practice-based, and general discussions, and which streams and fields of science provide these answers. Second, the research landscape is reviewed for theories,

models, and concepts of dementia that encompass multiple aspects of dementia, if possible, to gain an orientation to the current state of research on dementia in its entirety.

Introductory it must be pointed out that in the context of this work dementia is not differentiated into different forms. For this work, the phenomenon of dementia itself, in all its facets and references, is the guiding principle, not primarily differentiated according to specific symptoms, etiologies and therapies.

2.1 Definitions: What is dementia?

The challenge of answering the leading question of this chapter already starts with the terminology: dementia, with its original meaning "without mind" transferred from the Latin word *dementia* (Wißmann & Gronemeyer, 2008, 52), is a terminology that is not easy to describe in terms of content and, moreover, is mostly used synonymously with Alzheimer's disease by many people (Engel, 2011). An abstract definition of dementia does not seem to exist so far; the definition of the term is either emotionally determined by terms such as "disease of the century," "farewell to the ego," and the like (Wetzstein, 2005a, 11), or is often made via the diagnostic criteria of the leading medical science, as stated by Wetzstein (2005a) in her study on the ethics of Alzheimer's disease.

Definitions of dementia with the broadest possible validity are to be expected in various places in literature and other media: In the basic literature on dementia, by advocacy groups, by research institutions and health policy organizations.

The definitions of the World Health Organization (WHO) in the International Classification of Diseases (ICD-10) (DIMDI, 2010) and the American Psychiatric Association (APA) in the Diagnostic and Statistic Manual (DSM-IV) (Saß, Wittchen, Zaudig & Houben, 2003) can currently be regarded as the most authoritative guiding definitions. Wetzstein (2005a, 42) speaks of a certain monopoly position of both institutions in the classification of diseases. According to Wißmann & Gronemeyer (2008), these classification systems reflect "what is the basis for medical thinking and action" (Wißmann & Gronemeyer, 2008, 33, translated). Thus, it can be assumed that they can also be regarded as guiding definitional instances for dementia research.

ICD-10: Dementia (F00-F03) is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement.

https://icd.who.int/browse10/2016/en#!/F00-F09

DSM-IV: The main feature of dementia is the development of multiple cognitive deficits, with memory impairment and at least one of the following cognitive

impairments: Aphasia, Apraxia, Agnosia, or Executive Function Impairment. [...] (Saß, Wittchen, Zaudig & Houben, 2003).

Although there are differences (Wetzstein, 2005a; Wißmann & Gronemeyer, 2008), which are not reflected in the excerpts of the definitions presented here, both institutions answer the question "What is dementia?" with a description of dementia as a syndrome whose leading symptoms are cognitive disorders (Wißmann & Gronemeyer, 2008).

On the website of the Deutsche Alzheimer Initiative (2008), which can be regarded as the overarching advocacy group for people with dementia and their relatives in Germany, a definition of dementia can be found after the search steps 'Alzheimer's disease/dementia' and 'Frequently asked questions and answers':

Dementia is one of the most common health problems in older age. The term "dementia" comes from Latin and literally means "away from mind" or also "without mind". It is understood to mean disorders of mental-emotional performance occurring in different compositions, such as memory disorders and thinking difficulties with a clear awareness, speech disorders, changes in mood control and social behaviors, making it very difficult to cope with everyday life. Dementia can have many causes, with Alzheimer's disease [...] being the most common [...]. ("Deutsche Alzheimer Gesellschaft," 2008).

Also here the focus is on memory disorders, which according to this understanding are caused by Alzheimer's disease (and other diseases). Thus, a causality is named here: First the Alzheimer's disease appears, by which then the disturbances are caused.

The dementia guide of the Ministry for Family Affairs, Senior Citizens, Women and Youth (Bundesministerium für Familie, Senioren, Frauen und Jugend, BMFSFJ) (n.d.) provides an explanation of the term in the section 'Medical background'/'Dementia'.

Dementia is a umbrella term for more than 50 forms of the disease. They progress differently, but all lead to long-term loss of mental capacity. The causes of dementia are manifold. A basic distinction must be made between primary and secondary dementias. Secondary dementia is the result of another, already existing underlying disease. (BMFSJF, n.d.)

In this context, the answer to the question "What is dementia?" is a purely medically based statement that is reduced to naming the various clinical pictures. Clearly, dementia is named as a disease.

The Dementia Competence Network [Kompetenznetz Demenzen] (n.d.), as a research association of mainly psychiatric clinics, also aims in its definition of dementia at the concept of disease. The following definition on the website of the Competence Network is primarily

intended for people with dementia and their supporters. For the specialized public no own definition is given but referred to numerous guidelines.

Dementias are diseases that lead to the loss of mental and physical abilities, so that the affected persons in advanced stages can no longer lead an independent life. (Dementia Competence Network, n.d.)

Demenz Support Stuttgart (2010a) does not provide a literal definition of dementia on its website. The closest possible approximation to a form of definition that can be found there is part of the philosophy of the institution, which sees itself as a "mediator and moderator between the highly diverse groups of actors, professions, disciplines and perspectives involved in addressing the societal challenge of dementia" (Demenz Support Stuttgart, 2010a). A medical definition or a definition of a disorder is searched for without success.

Dementia confronts us with crucial social and cultural challenges. Real improvements will only be achieved if we say goodbye to ingrained patterns of perception and prevailing attitudes. (Dementia Support Stuttgart, 2010a)

A definition of what dementia is, can also not be found on the website of Aktion Demenz e.V. (n.d. a). However, an answer to the question "What is dementia?" becomes clear in the Esslingen Appeal of the initiative (Aktion Demenz, n.d. b), but focuses on the people with dementia, not dementia itself:

```
People with dementia are citizens! [...]
People with dementia do belong! [...]
People with dementia have rights! [...]
People with dementia concern us all! [...]
People with dementia need our fantasy! [...]
(Aktion Demenz, o.J. b).
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Here, a citizenship or civil society understanding of dementia becomes obvious.

The comment by Wetzstein (2006), who, as a representative of an ethical perspective on dementia, criticizes the absolutization of the medical perspective on the overall debate, appears as a summary of these definitions and positions on dementia: "However, a biomedical concept of dementia, which was absolutely appropriate for medicine, now found its way into the social discourse on dementia, to a certain extent via a supposed scientific objectivity." (Wetzstein, 2006, 39). In the definitions and viewpoints on dementia presented here, the dominance of this biomedical concept becomes visible. Many institutions involved in the topic refer to a disease concept as a characteristic of dementia and focus especially on memory impairment. Nevertheless, with Demenz Support Stuttgart and Aktion Demenz, two institutions clearly differ from this concept, so that it is no longer possible

to speak of a general dominance of the discussion by the medical definition, even if this clearly predominates in the selection of definitions presented here.

A brief overview of some definitions and explanations of terms in foundational literature on gerontology and dementia will clarify the extent to which the picture that has emerged so far of a medically dominated definition oriented toward disease or disorder is also represented in this field, or whether a different picture is emerging.

In their Introduction to Gerontology [Einführung in die Gerontologie], Wahl and Heyl (2004) see dementia as a disease. Förstl (2009a), in the basic work Dementias in Theory and Practice [Demenzen in Theorie und Praxis], refers to the ICD-10 when answering the question What is dementia? and describes the dementia syndrome as "a secondary deterioration of a previously greater mental capacity" (Förstl 2009b, 4, translation). Mahlberg and Gutzmann (2009b) also refer to dementia disorders in Recognizing, Treating, and Caring for Dementia [Demenzerkrankungen erkennen, behandeln und versorgen]. Kieckebusch (2010) differentiates in her Psychological Dementia Diagnosis [Psychologischen Demenzdiagnostik] that dementia is "in the narrower sense not a disease, but rather an increasing impairment of mental performance or a brain-organic pathological degradation" (Kieckebusch, 2010, 17, translation). The S3 Guideline Dementias, in the development of which the Deutsche Alzheimer Gesellschaft was also involved, formulates: "Dementias are defined by the degradation and loss of cognitive functions and everyday skills." (DGPPN & DGN, 2009, 11, translation). Thus, the basic literature cited here is relatively clearly oriented to a disease or disorder concept.

Finally, a look at the perspective of those affected gives a little insight into the fact that a medically dominated picture is not helpful or sufficient for all people involved in the phenomenon of dementia. People with dementia are also first confronted with the classical definitions of dementia. For example, Taylor (2008), an American psychologist affected early by dementia, says dementia is "a pattern of symptoms suggestive of one disease or a combination of several diseases" (Taylor, 2008, 36), but formulates a little later, "From my point of view, from that of a person living with this diagnosis [Alzheimer's disease, B.W.], far too much importance is given to the label, the name, and the symptoms that usually accompany the condition, whereas too little importance is given to the people who have the disease." (Taylor, 2008, 42). From the internal perspective of dementia, the attempt to define it, as attempted here from a scientific perspective, is seemingly irrelevant, at least to some persons affected.

Summarizing, Wetzstein's (2005a) research findings in which she states a lack of abstract definitions still seem to be relevant, as does the dominance of a medical model she notes. "Anyone who follows the public debate about Alzheimer's disease in the media is struck by the following: Alzheimer's disease appears as a purely medical problem for which physicians alone are considered competent." (Wetzstein, 2005a, 38). In many cases, dementia seems to be nothing more than a disorder, a disease. Other aspects, such as the civic

approach represented by Demenz Support Stuttgart and Aktion Demenz, are only slowly coming into the focus of (scientific) debate.

Therefore, in the following, the state of research on dementia concepts as further explanatory models will be considered in more detail.

2.2 Concepts and models of dementia

Beyond the mere definition of dementia as presented in the previous paragraph, there are many detailed explanations for dementia. Following Wetzstein (2005a), the term "dementia concept" will be used for these in the following. In Wetzstein's study on an "Ethics of Dementia" [Ethik der Demenz] (2005a), the state of research on concepts of dementia was presented, so that this work can build on these results. As already shown in the previous section, Wetzstein's findings on the definition of dementia have changed little since 2005.

Wetzstein (2005a) explores the term dementia concept in detail. So she identifies, among others, dementia concepts of the constructivist tradition, which she rejects because no moral differentiation of different positions is possible (Wetzstein, 2005a, 15). Furthermore, she identifies concepts by and in the tradition of Tom Kitwood, which she likewise rejects as moderately constructivist, among other things because the model opposed to the medical model does not appear to be feasible (Wetzstein, 2005a, 15). More recent approaches by Post and Whitehouse, to which she attests a similar (i.e., ethically oriented) goal as her own concept, are, however, subject to the shortcoming, in Wetzstein's view, "that they do not take the trouble to systematically elaborate criteria of the current dementia concept" (Wetzstein, 2005a, 15). According to her research, a purely medical concept of dementia dominates, even though she acknowledges at a later point that there are also approaches in medicine to open to insights from, for example, social psychology (Wetzstein, 2005a).

It [Wetzstein's study, B.W.] is based on the hypothesis that the Alzheimer's disease problem complex is currently based on a dementia concept determined by scientific criteria. This current dementia concept is first of all based on medical statements about dementia and has implications and consequences from here. Since medicine, in pursuing its own mission of diagnosing disease and curing or alleviating suffering, never acts on phenomena without presuppositions, the current dementia concept is necessarily based on limitations. If this supposedly comprehensive concept is transferred to the public, the phenomenon of Alzheimer's disease experiences a significant reduction. (Wetzstein, 2005a, 16)

Wetzstein is not the only one with this criticism of the medically dominated dementia concept. Wißmann and Gronemeyer (2008) also call for a critical discussion of ICD-10 and DSM-IV and formulate as a goal "a broadly conducted debate about a new and holistic dementia definition, which would have to be the basis of all social groups, not the only one of

medicine" (Wißmann & Gronemeyer, 2008, 33). Dammann and Gronemeyer (2009) justify their criticism of medicine and the billion-dollar business with dementia as follows:

Until today, no clear biological-organic causes could be identified in the majority of people suffering from "brain disorders", so that most dementia diagnoses are in fact interpretations, i.e., nothing but the interpretation of symptoms. (Dammann & Gronemeyer, 2009, 12)

Finally, Whitehouse and George (2009) 'debunk' the myth of Alzheimer's, take an unequivocal stand against the interpretive sovereignty of medicine in matters of dementia, and advocate a modified concept of dementia, which in their case consists of accepting the changes defined by medicine as dementia as part of normal brain aging and adjusting one's life accordingly (Whitehouse & George, 2009).

Looking at the alternative concepts and models proposed, the respective authors turn away from the medical definitional sovereignty in their concept development, but contrast the previous model with new concepts, which are often also entrenched in a perspective stance, such as Wißmann and Gronemeyer (2008) with their civil society approach, and Whitehouse and George (2009) with their brain aging approach.

However, what all recent concepts have in common (Wetzstein, 2005a; Whitehouse & George, 2009; Wißmann & Gronemeyer, 2008) is that they call for a holistic, integrative approach and want to see other relevant sciences included.

Dementia cannot be the concern of a single or a few disciplines. Dementia concerns everyone! Ethics, medicine, culture, philosophy, education, sociology, nursing, theology, psychology and anthropology: they all have an equal contribution to make to the discourse. Scientists, politicians and care practitioners, family caregivers, civic activists, people with dementia, young and old: they all have a voice. (Wißmann & Gronemeyer 2008, 76)

Both the approaches of Wetzstein (2005a) with a theological-ethical orientation and Wißmann and Gronemeyer (2008) with their civil society model are important approaches on the way to a comprehensive dementia concept. However, they leave out aspects that are equally important components of the phenomenon of dementia, such as economic or macroeconomic issues (Kiencke, Rychlik, Grimm & Daniel, 2010), the question of the spatial-architectural integration of dementia (Marquardt, 2006) or the literary processing of the phenomenon (Schnell & Mitzkat, 2006). The concepts considered in depth here (Wetzstein, 2005a; Whitehouse & George, 2009; Wißmann & Gronemeyer, 2008) are thus comprehensive in their perspective orientation, but not far-reaching enough to give space to as many aspects of the phenomenon of dementia as possible or to offer points of connection also for marginal topics. It should be noted, however, that none of the concepts mentioned makes this claim for itself.

2.3 Summary

Based on the findings of several studies, in this chapter it could be shown that in the current professional as well as general discussion a medically dominated picture prevails, which however - this could also be shown to some extent - is not sufficient to meet and correspond to the concerns of all participants and the challenge of dementia on all levels. In the definitions of some important institutions in the context of dementia, a dominance of a medical disease concept of dementia could be found. Both in these and especially in the basic guidelines (ICD-10, DSM-IV, S3 Guideline on Dementias [S3-Leitlinie Demenz]), terms such as disorders, disease and reduction dominate (cf. ch. 2.1). The same applies to the professional literature (cf. ch. 2.1). Newer approaches of concepts, which want to abolish the dominance of medicine, are available, but remain connected to a perspective view (cf. ch. 2.2).

In the following chapter, Integral Theory will be presented as a theoretical model that claims to be so comprehensive that it can largely integrate or link all aspects of an issue.

3 The Integral Theory according to Wilber

In the above outlined state of research, it became clear that conventional dementia concepts are dominated by a medical understanding of dementia. Various areas seem to have been left out so far, or have only been poorly covered by scientific research, as scientists, people with dementia and advocacy groups increasingly complain (Taylor, 2008; Wetzstein, 2005a; Whitehouse & George, 2009; Wißmann & Gronemeyer, 2008).

The goal of this paper is to develop a blueprint for a dementia concept that can integrate as many perspectives as possible. In order to take into account the different perspectives of people with dementia, relatives and scientists of different disciplines, treating physicians, caregivers, but also other stakeholders, a multidimensional framework is needed that allows and includes many perspectives on an equal footing.

The Integral Theory according to Ken Wilber (2001a, 2006a) claims for itself a multidimensionality that makes it possible to include previously competing views and concepts of scientific research, practical activity as well as individual experiences in an explanatory model.

The word integral means comprehensive, inclusive, non-marginalizing, embracing. Integral approaches to any field attempt to be exactly that: to include as many perspectives, styles, and methodologies as possible within a coherent view of the topic. In a certain sense, integral approaches are "meta-paradigms," or ways oto draw together an already existing number of separate paradigms into an interrelated network of approaches that are mutually enriching. (Wilber, quoted in Esbjörn-Hargens, 2009, 1)

Integral Theory is a rapidly growing current within the large field of integral studies since the early 1980s, building on the work of American philosopher Ken Wilber (for the distinction between integral theory and integral studies, see Esbjörns-Hargens, 2009). Drawing on the work of preceding integral theorists, such as Teilhardt de Chardin and Jean Gebser (McIntosh, 2009), Wilber developed his integral explanatory model for phenomena of consciousness in numerous publications (including Wilber, 2001, 2005a, 2006, 2007). The model is also known as the integral approach, quadrant model, or AQAL (all quadrants, all levels), and is increasingly used in various professions and scientific fields (Esbjörn-Hargens, 2009; Integral Research Center, 2009). In recent years, Integral Theory has also been increasingly received in German research (Fuhr & Gremmler-Fuhr, 2004; Weinreich, 2005; Küpers, 2006; Wittrock, 2008).

Even though Integral Theory is understood as a theory by many theorists and users, it should be noted that it is often referred to as a worldview (Wikipedia, Integral Theory), and is subject to numerous criticisms in terms of scientificity (for this, see, among others, the discussion pages of the German and English Wikipedia articles on Integral Theory; de:Wikipedia, Diskussion:Integrale Theorie; en:Wikipedia, Integral Theory; en:Wikipedia,

Talk:Integral Theory). For a more in-depth discussion of the critics of Integral Theory, I refer to McFarlane (2000), McIntosh (2009), and Meyerhoff (2006) as examples.

Despite these criticisms, this thesis connects to the increasing acceptance and application of Integral Theory in the German and international scientific community (see references above). By applying the theory as an epistemological model, it aims to contribute to a broader view of dementia, not to a fundamental discussion of Wilber's Integral Theory.

In this work, Integral Theory is intended to serve as an epistemological guideline for the theoretical elaboration of a dementia concept that provides a framework for bringing together the various currents and explanatory models surrounding the phenomenon of dementia. In order to present the theory in its claim of a comprehensive approach (Wilber, 2007) as a framework for an integral dementia concept, it will first be described in its basic elements without already making references to the subject area of dementia. While chapter 3.1 presents the basics of Integral Theory, chapter 3.2 will present the possibilities of its scientific application. Chapter 3.3 gives a summary of Integral Theory with regard to an integral research process.

3.1 Fundamental principles of Integral Theory

A basic assumption of the Integral Theory is the evolutionary principle as the basis of all phenomena that have developed since the Big Bang, which almost all sciences agree to be the starting point of all being on earth (Wittrock, 2008).

Evolution is a wildly self-transcendence process: it has the utterly amazing capacity to go beyond what went before. So evolution is in part a process of transcendence, what incorporates what went before and then adds incredibly novel components. The drive to self-transcendence is thus built into the very fabric of the Kosmos itself. (Wilber, 1996, 23)

Furthermore, it is assumed that evolution always moves in the direction of increasing complexity with increasing differentiation and increasing structuring, whereby the newly emerging higher levels always include and transcend the lower levels (Wilber, 2000a).

The concept of the holon is another basic assumption of Integral Theory (Wilber, 2000a). It states that in both biological and social contexts there are no entities that are completely independent of each other, whereby entity can be understood as a collective term for everything that is, or also as the "unspecified existence of something" (de:Wikipedia, Entität). The individual forms of existence are always embedded as individual parts in a whole and at the same time consist as a whole of different parts, which in turn are each independent wholes (and parts). "Each of these entities is neither a whole nor a part, but a whole/part, a holon." (Wilber, 1996, 20). Each holon stands in a hierarchical relationship to its higher level (from which it is included and transcended) and to its lower level (whose various parts it includes and transcends). This hierarchy of wholes that are part of another whole

(de:Wikipedia, Holon) is also called holarchy. Development, according to this understanding, occurs through inclusion and transcendence of what has gone before (Wilber, 1997). All higher evolved entities (such as humans) have emerged from continuous transcendence of 'lower' entities (atoms, cells) without ceasing to exist, but being included in the higher evolved form.

From the findings about holons and holarchies came the further conclusion that all holons appear in four dimensions. All holons have an individual and a collective manifestation. "For example, where there is individual consciousness, there is a collective culture to which that individual belongs. And as the consciousness of the individuals within a culture evolves, so does the culture as a whole." (McIntosh, 2007, 220). Each holon further has an inner dimension and an outer dimension that are always evolving in interdependence. "Wilber also recognized that as the complexity of a biological organism's exterior form increases, there is a corresponding increase in the complexity of that organism's consciousness." (McIntosh, 2007, 219). In short, there is always an inside and an outside, a singular and a plural. Intertwined with each other, they represent four dimensions of reality, "at least four irreducible perspectives (subjective, intersubjective, objective, and interobjective) that must be consulted when attempting to fully understand any issue or aspect of reality." (Esbjörn-Hargens, 2009, 2). The multi-perspectivity of reality is consequently another basic integral assumption, whereby it is assumed that every occurrence continuously unfolds in these four dimensions (Wilber, 2006a).

In summary, Integral Theory aims to bring together a wide variety of theories, methodologies, and strands to an issue so that it can be viewed from multiple perspectives of equal importance. Originally based on insights from consciousness research and psychology (Wilber, 2000b), Integral Theory "weaves together the significant insights from all the major human disciplines of knowledge, including the natural and social sciences as well as the arts and humanities" (Esbjörn-Hargens, 2009, 1). For this purpose, it makes use of so-called structural elements that differentiate and clarify the development of holons or entities of consciousness in different fields and at different levels. According to the understanding of the Integral Theory, development takes place in the four areas already identified in the context of the holons, which are called quadrants. In each of these, developmental processes occur in different characteristics over different developmental phases (Weinreich, 2007, 2). Integral terminology uses the term lines for these properties and calls the phases levels. The recognition that development in certain areas often proceeds according to certain patterns (types), and temporally limited, changing states in or around the entity influence what happens, completes the integral understanding of development. Thus, five structural elements (quadrants, lines, levels, types, and states) emerge that together provide a model for describing the reality of a single phenomenon. They are presented in the following sections.

3.1.1 The quadrant model

With the quadrant model of Integral Theory (Fig. 1), Wilber has developed a graphical model that provides a well-understood framework for currently practiced integral thinking, research, and action. Despite some criticism (e.g., McFarlane, 2000), it is considered by many integral theorists to be the best current model for explaining the integral frame of reference (Esbjörns-Hargens, 2009). Criticism of the external-collective quadrant in particular is expressed by McIntosh (2007), but he himself says at the same point, "Despite its limitations, I think we can continue to use the quadrant model as long as we do not take it too literally." (McIntosh, 2007, 230). In this sense, the quadrant model and its structural elements, described in the following sections, should be understood here as an epistemological guide to a thinking and research process, not as a literal dogma to be followed.

The quadrant model (Fig. 1) visualizes that each fact or holon is differentiated into the four domains derived in the previous section, here called quadrants: The upper quadrants stand for the individual parts, the lower quadrants for the collective parts. The left quadrants stand for the internal, the right quadrants for the external aspects of a holon.

| | INTERIOR | EXTERIOR |
|------------|--|--|
| INIVIDUAL | Interior-individual dimension Subjective perspective "I" | Exterior-individual dimension Objective perspective "It" |
| COLLECTIVE | Interior-collective dimension Intersubjective perspective "We" | Exterior-collective dimension Interobjective perspective "It (plural)" |

Fig. 1: Quadrant model, own illustration based on Wilber 2006; Esbjörn-Hargens 2009.

The upper left quadrant refers to the aspects of a holon from the inner-individual perspective. This area represents the inner processes accessible only to introspection, and is discussed in particular detail in most integral works. Phenomena such as "consciousness" (Wilber, 2001a,b) and "meditation" (Wilber, 2006a), which are intensively explored and practiced in the integral movement, are assigned to this quadrant. Here we are concerned with the subjective processes, with the 'I'.

In the upper right quadrant are found the aspects of a holon from the external-individual perspective. This is the area of observable behaviors and externally perceptible facts on the individual level, the area of objective aspects, the 'It'. This quadrant shows "what any individual event looks like from the outside." (Wilber, 2006a, 21).

The lower left quadrant is concerned with the internal perspective of collective phenomena. Here all cultural, commonly internalized aspects of a collective are considered; it is the realm of intersubjective understandings, the 'we'. "In the lower left quadrant we find the collective internal meanings that make up the worldview or shared world-space of social or communal holons." (Wilber, 2006a, 165).

The lower right quadrant gathers together all the external-collective aspects, the externally perceptible and measurable parts of a collective, a social system. It is the realm of the social environment, the 'they' (or also called 'it' plural). The individual is of interest here only insofar as it is part of a particular network or system whose functionality is central. "The Lower-Right quadrant, in other words, represents all the exterior forms of social systems, forms that also can be seen, forms that are empirical and behavioral [...]." (Wilber 2000, 128).

The quadrants thus illustrate that 'reality' appears in different dimensions, and that - if one wants to represent reality as comprehensively as possible - one has to approach it from many different perspectives. Each quadrant represents reality, but not the whole reality, but one aspect, one dimension of reality. In recent works Wilber (2006a) additionally distinguishes between quadrants (the perspective of a subject) and quadrivia (the perspective on an object) and puts forward the thesis that only for individual holons quadrants and quadrivia (i.e. the perspective of the subject and that on the object) are possible, but artifacts (for example a Coke bottle, cf. Wilber, 2006a) can only be viewed from a perspective on an object, i.e. they do not 'have' quadrants but only quadrivia (Wilber, 2006a). However, since the problem of artifacts is of only minor interest in the case of the present topic, further discussion of quadrivia will be left out here.

Similarly complex as the quadrivia, the Integral Theory becomes through the so-called zones, which are created by adding an external perspective to each quadrant. These eight zones, introduced in the recent work of Wilber (2006a), will be presented in more detail in chapter 3.2 within the framework of Integral Methodological Pluralism because of their relevance for scientific research.

At this point, the description of the structural elements of Integral Theory continues with the model of lines. It should be noted that in this work we deviate from the usual order of description in Integral Theory (first levels, then lines, cf. Esbjörn-Hargens, 2009; Wilber 2006a), as it seems to me to be the more sensible order for the later application to dementia as well as for the underlying understanding of development: development happens in different domains (lines) and extends within them over different levels.

3.1.2 Lines of development

The lines of development, also called streams (Wilber, 2001a), describe the phenomenon that development takes place in different areas within a quadrant. Individuals can reach different levels of development in different abilities, cultures are at different levels of

development in different areas, states are differentiated differently in the individual areas of their organization.

Lines of development exist in all quadrants. "An integral practitioner can use lines as a diagnostic tool to ensure that these aspects are recognized and effectively addressed by individuals or groups." (Esbjörn-Hargens 2009, 9). The developmental lines of one quadrant correlate with those of other quadrants. Thus, neurophysiological changes in the external-individual realm cause changes in the line of consciousness in the internal-individual realm (and vice versa), which in turn affects lineages in the culture and system of the person concerned (Wilber, 2000). However, this does not mean that there is always uniform development in all domains and in all lines; on the contrary, development occurs to different degrees and at different speeds in different lines (Wilber, 2006a).

[...] some lines are necessary but not sufficient for others; some develop closely together. But on balance, many of the streams develop at their own rate, with their own dynamic, in their own way. A person can be at a relatively high level of development in some streams, medium in others, and low in still others. Overall development, in other words, can be quite uneven. (Wilber, 2001a, 44)

The upper left quadrant is the best documented area in the integral literature in terms of lines of development (Wilber, 2006a). The lines in other areas are rarely elaborated in detail by Wilber; however, the reception of Integral Theory by Esbjörn-Hargens (2009, 11) shows a differentiation of the other quadrants. The following figure 2 shows some exemplary lines in the respective quadrants.

| | INTERIOR | EXTERIOR |
|------------|--|---|
| INIVIDUAL | Cognitive awareness Moral awareness Spiritual experiences Access to emotions | Neurotransmitters Brain wave patterns Skeletal muscle growth Food intake |
| COLLECTIVE | Worldviews Religious understandings Cultural values Intersubjective dynamics | Geopolitical structures Ecosystems Legal codes Architectural styles |

Fig. 2: Different lines in the quadrants, own illustration based on Esbjörn-Hargens, 2009.

Within the individual lines, different phases of development can usually be described. These phases, called levels in Integral Theory, are explained in the following section.

3.1.3 Levels of development

Levels of development describe the phenomenon that development occurs continuously (albeit in different tempi) in the separate lines of the different quadrants. Growth or development proceeds in successively building levels (Fig. 3). Wilber (2001a) also speaks of waves of development, since a rather smooth transition from one level of development to the next is assumed. Occasionally, the term development stages is also used. However, since a developmental process rarely involves (or can be measured as) a clearly definable step up or down a level, the term levels or waves seems more appropriate, even though the level model shown in Figure 3 below suggests a stage-like progression of developmental levels.

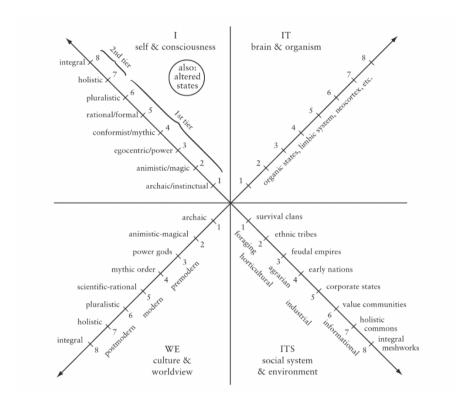


Fig. 3: Typical models of levels of the Integral Theory, Wilber 2001a.

The level model illustrated in Figure 3 using exemplary areas makes it clear that reality is a dynamic process, not a static persisting state. The levels represent the development of a holon over time, with the levels of the left quadrants representing the (increasing) depth of a development, and the levels of the right quadrants representing the (increasing) complexity of an issue (Esbjörn-Hargens, 2009).

Levels or waves in each quadrant represent a holarchy, a kind of hierarchy in which each new level transcends the boundaries of the previous levels but includes the essential aspects of those very levels. Consequently, each wave inherits the wave of the past and adds a new level of organization or capacity. (Esbjörn-Hargens, 2009, 8)

One of the best-known level models for the upper left quadrant that is drawn upon in the integral movement is Spiral Dynamics (Fig. 4), a developmental approach by Graves (Wilber, 2001a) that Beck and Cowan (2008) have extended. The model describes the development of value orientation using a spiraling upward model in which growth and development occurs as a smooth transition from one level to another (Beck & Cowan, 2008).

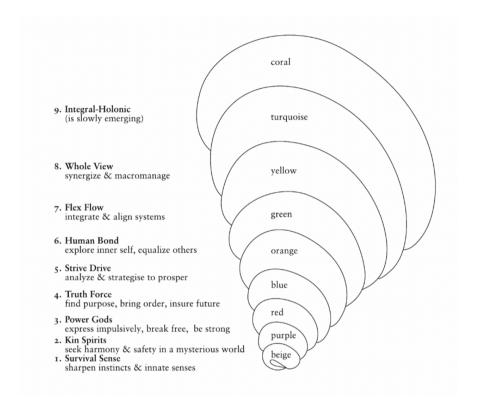


Fig. 4: Spiral Dynamics according to Beck & Cowan, 1995, Wilber, 2001a, 20

This model clarifies the understanding of levels, not stages, in which development occurs within a domain.

However, developmental processes not only differentiate into lines and levels, but further differentiate, as will be outlined in the following section, into specific typologies that can be of different types within each quadrant.

3.1.4 Types

In all quadrants - and in all areas of development - one finds various typologies that must be taken into account when dealing in an integral way with an issue. Typologies show up within lines, levels and states. They mean nothing else than that within a domain two or more different kinds of development can take place, which are typical in a certain way, that is, can proceed in the same way in individuals, holons of the same kind and the same specific properties. "Typologies are, technically speaking, an expression of horizontal variance." (Habecker, 2010, 8). The simplest typology for the two upper quadrants is the distinction between male and female, i.e., gender types; another type model cited by Wilber (2001a) is the Enneagram, a personality typology of Sufi tradition that differentiates nine

different types of cognitive-emotional behavior patterns (Palmer, 1991). However, typologies can also be found in all other quadrants (cf. Fig. 5), which illustrate that development in different individuals or collectives can proceed similarly in defined areas if certain identical initial conditions are present.

| | INTERIOR | EXTERIOR |
|------------|--|--|
| INIVIDUAL | Consciousness and personality types: masculine/feminine Enneagram Learning styles | Behavior and body types: Blood groups Gender types Somatotypes Perception types |
| COLLECTIVE | Types of relationship and of society: Religions (Christian, Hindu, Buddhist) Couple relationships (m/f, m/m, f/f) | Organizational and systemic types: Systems of government Ecosystems General systems (open, closed, dynamic, static, interactive) |

Fig. 5: Types in the quadrants, own illustration based on Habecker, 2010, Esbjörn-Hargens, 2009.

The consideration of the effects of a typology on the levels of a line of a quadrant, if necessary still with the addition of different states, assumes a degree of complexity, which is theoretically nameable, in the application in detail however probably only very laboriously convertible.

As the last structural element of the Integral Theory, the states follow in the next section as an element of temporally changing internal as well as external framework conditions for development processes.

3.1.5 States

The structural element of states, the final component of the Integral concept, is perhaps the most controversial element of Integral Theory in the scientific community, as exemplified by Belschner's (2010, 107) experience in the efforts to integrate Transpersonal Psychology into the scientific community. States can be identified in all four quadrants, as Figure 6 exemplifies.

| | INTERIOR | EXTERIOR |
|------------|--------------------------------------|-----------------|
| INIVIDUAL | States of Consciousness | Hormonal States |
| COLLECTIVE | Group States (e.g. Mass Hysteria) | Weather States |

Fig. 6: Exemplary states in the quadrants, own representation based on Esbjörn-Hargens, 2009.

Esbjörn-Hargens (2009) describes the states-referring to all four quadrants-as "temporary manifestations of aspects of reality" (ibid.) and further remarks, "They also tend to be incompatible with each other." (ibid.). Waking state and deep sleep are mutually exclusive, likewise snowstorm and sunshine are usually mutually incompatible states; this is also true of many states in other quadrants.

In Wilber's writings, the various states of consciousness have their place primarily in the external-individual quadrant.

The inclusion of states is useful for practitioners because our realities both internally and externally are always shifting—all kinds of state changes occur throughout our day within ourselves and our environments. Including states allows us to understand many of the ways these shifts occur and why. (Esbjörn-Hargens, 2009, 13)

For the subjective quadrant, Integral Theory specifically refers to the natural states of consciousness: gross waking state, subtle dream states, causal formless states, state of the witness, and non-dual awareness (Wilber, 2006a.). For the other quadrants, differentiated state models are hardly found in the integral literature.

3.1.6 Summary of the structural elements of Integral Theory

In the previous sections, the essential elements of Wilber's Integral Theory were presented. They form the basic framework by which a matter can be structured and the interconnections of its individual elements can be represented among each other. The way goes from a differentiation into four large areas of reality, the quadrants (ch. 3.1.1) or also called dimensions, further to the different lines (ch. 3.1.2) as the areas in which development takes place within each quadrant. Within these lines, development is a processual event that can usually be described in terms of different levels (ch. 3.1.2). Finally, these

development processes differ again depending on the type (chap. 3.1.4) within which they take place and the states (chap. 3.1.5) to which they are subject.

The approach of Integral Methodological Pluralism (Wilber, 2006a), which will be explained in the following section, now points out the significance of these elements within scientific research and in which form they can be used.

3.2 Integral Methodological Pluralism

The approach of Integral Methodological Pluralism (IMP) (Wilber, 2006a; Wilber, 2006b; Wittrock, 2008) provides the framework to facilitate the application of Integral Theory and its structural elements presented in chapter 3.1 to concrete fields of work and epistemology. Against this background, Integral Theory is also useful in scientific research, as IMP makes the path of integral ways of knowing comprehensible and verifiable. There is no strict separation between the quadrant model and Integral Methodological Pluralism, as it might appear due to the structurally necessary subdivision of this work; rather, IMP is the extension and differentiation of the quadrant model.

Integral Methodological Pluralism (IMP) involves, among other things, at least 8 fundamental and apparently irreducible methodologies, injunctions, or paradigms for gaining reproducible knowledge (or verifiably repeatable experiences). The fundamental claim of AQAL Integral Theory is that any approach that leaves out any of these 8 paradigms is a less-than-adequate approach according to available and reliable human knowledge at this time. (Wilber, 2006a, 33).

Beyond the eight zones presented in section 3.2.2, the validity claims in section 3.2.1 can also be seen as a criterion for the responsibilities of different epistemological traditions as part of the IMP, as well as the approach to integral cognition described with the three strands in section 3.2.3. This section begins with the validity claims, as they can be seen as fundamental to the subsequent integration of the zones into the integral model.

3.2.1 Validity claims

From the structural elements outlined, integral research has the requirement to look at each issue from four interwoven perspectives. These four perspectives are represented by different schools, which so far have appeared as competitors rather than partners in science. As a representative, Wilber (11997) names scientific traditions and representatives of theoretical positions that have formulated their standpoint as representatives of 'truth' primarily also by distinguishing themselves from other methodologies and traditions.

Each approach is giving us, as it were, one corner of the Kosmos. Each is telling us something very important about various aspects of the known world. And none can be reduced to the others without aggressive and violent rupture, distortion, dismissal. (Wilber, 1997, 12)

It is undisputed that all fields of science have produced important insights in their areas of competence (Wilber, 1997). Figure 7 gives an overview of some scientific and general epistemological traditions of the respective quadrants.

| | INTERIOR | EXTERIOR |
|------------|---|--|
| INIVIDUAL | Psychoanalysis Depth Psychology Buddhism Piaget's Theory of Cognitive Development | Empiricism Behaviorism Skinner's Theory of Operant Conditioning Natural Sciences (Biology, Physics) |
| COLLECTIVE | Kuhn's Paradigm Concept Hermeneutics Sociology of Max Weber | Systems theory Sociology Karl Marx Ecological-Evolutionary Social Theory |

Figure 7: Influential schools in the quadrants, own illustration based on Wilber, 2005a.

Criticized by the representatives of Integral Theory is that the different epistemological traditions claim to grasp truth for the whole without recognizing or admitting that their knowledge is 'true' but that this truth is only valid for a certain domain with certain injunctions and methodologies (what is also called quadrant absolutism in Integral Theory; Wilber, 2006a).

Wilber names interpretation and hermeneutics as representative methodological approaches for the two inner quadrants; he also calls science in these domains the 'broad sciences'. The methodological approaches representative of the two right quadrants are empiricism and positivism; these scientific tradtions are characterized as the 'narrow sciences' (Wilber, 2001a). All quadrants have different validity claims for epistemology, by which Wilber refers to Habermas' theory of validity claims (Wilber, 1997, cf. Fig. 8).

Each of these "four quadrants," in fact, has its own particular type of truth or type of "validity claim" — the ways in which it goes about accumulating and validating its data and its evidence. [...] And to say that none of these quadrants can be reduced to the others is to say that none of their respective truths can be dismissed or reduced, either. (Wilber, 1997, 12)

| | INTERIOR | EXTERIOR |
|------------|--------------|----------------|
| INIVIDUAL | Truthfulness | Truth |
| COLLECTIVE | Justice | Functional Fit |

Fig. 8: Validity claims according to Habermas, own illustration based on Wilber, 2005a.

For the inner-individual quadrant, Wilber cites, among others, Freud, C.G. Jung, Jean Piaget, but also Aurobindo and Gautama Buddha as representatives of the ways of knowing of this quadrant (Wilber, 1997, 2001a). He calls it a "place of the 'inner' sciences" (Wilber, 2000, 161), whose most important epistemological traditions include psychoanalysis and phenomenology. The validity claim according to Habermas for an inner-individual researching science is subjective truthfulness. It is not a matter of obtaining objective data. Research in this quadrant makes use of subjective data obtained from the inner experience of individuals. "The validity claim here is not so much whether my statements match exterior facts, but whether I can truthfully report on my own inner status." (Wilber, 1997, 14).

Behaviorism, neurology, physics, and biology are mentioned as concrete epistemological traditions of the external-individual quadrant (Wilber, 1997).

Behavior can be seen, it is empirical — which is precisely why empirical science is always concerned only with the behavior of holons (the behavior of atoms, the behavior of gases, the behavior of fish, the behavior of humans) and wants nothing to do with nasty ol' introspection, which involves, of course, the interiors of individuals. (Wilber, 2000, 128)

The validity claim of truth applies to this area of the empirical sciences. Wilber (1997, 52), following Habermas, speaks of a propositional truth that becomes 'true' by being consistent with an objective state of affairs. This validity claim not only holds in large areas of science, but also corresponds to most people's common understanding of truth in everyday life. What is true is what can be measured in some way according to defined criteria. "So common is propositional truth that it is often just called "truth" for short." (Wilber, 1997, 13). Thus, in integral terminology, when people speak of truth in their everyday life contexts, they are referring to the truth of the upper right quadrant - a truth that is based on measurable, objective data.

As in the inner-individual quadrant, the methodological approaches to the inner-collective quadrant are interpretive and hermeneutic; concrete scientific traditions are, for example, ethnology and ethics. The validity claim of this area is called justice. Sciences of this quadrant operate in the intersubjective space of trying to "understand how subjects fit together in acts of mutual understanding" (Wilber, 1997, 16). Based on the proposition that a shared cultural, ethical, and moral space is required for a functioning community between two or more individuals (ibid.), scientific knowledge seeking in this quadrant asks how to shape and influence a coexistence that is conducive to growth for all individuals. "This intersubjective space (our commonly shared background contexts and worldviews) is a crucial component of the human being, without which our individual subjective identities could not even exist, and without which objective realities could not even be perceived." (Wilber, 1997, 17).

The methodologies of the external-collective quadrant are again empiricist and positivist; many fields of sociology, economics, and especially systems theory are typical scientific traditions in this quadrant. In keeping with the empirical methodology, the validity claim of this quadrant is the functional fit. "And it is the objective behavior of the overall social action system, considered from an empirical stance, that forms the yardstick by which truths in this domain are judged." (Wilber, 1997, 16).

Based on the validity claims, the following section describes the quadrants with the zones as expressions of inside and outside views of the respective object.

3.2.2 Methodological pluralism: quadrants and zones

In his most recent work, Wilber (2006a) additionally differentiates the quadrants, especially with regard to scientific ways of knowing, into an inside view and an outside view from which the phenomena of the respective quadrant are perceived (for details cf. Wittrock, 2008) and names these eight emerging perspectives as zones (Wilber, 2006a), to which he vicariously assigns certain methodologies, as exemplified in Figure 9.

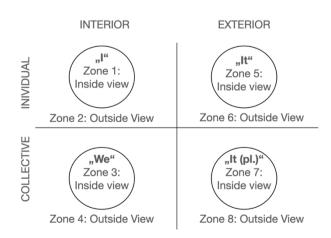


Figure 9: Zones in the quadrant model, own representation based on Esbjörn-Hargens, 2009.

It should be noted in the illustration in Figure 9 that the numbering of the zones (following Wilber, 2006a) follows first the two left-sided, i.e., inner quadrants, then the two right-sided, outer quadrants, whereas in all other contexts of the quadrant model in Integral Theory, also in many of Wilber's publications (2001, 2006a), the upper, individual quadrants are addressed first, then the lower, collective quadrants. In short: In the case of the zones, the numbering runs first to the left, then to the right; in all other contexts, the consideration usually follows the order first above, then below. With the exception of this chapter, this thesis also follows the latter order.

3.2.2.1 Methodologies of the inner-individual dimension

Research in the upper left quadrant deals with the inner experience of individuals and thus faces the challenge that the structures to be researched are nowhere visible in the external world (Wilber, 2006a). This challenge is particularly evident in the first zone, because in zone 1 research is concerned with the inside view of the internal phenomena of an individual holon. The exemplary methodology of this zone is phenomenology, but introspection, meditation, or contemplation are also considered methodologies of this zone (Wilber, 2006a). Zone 1 insights are often gained from the exploration of states of consciousness. "All of these methodologies consider objects in the stream of consciousness as they show themselves." (Wittrock, 2008, 49, emphasis in original). From the point of view of representatives of right-sided, empirical research, this area diminishes the scientific claim of Integral Theory, since here (scientific) knowledge resides in the subject itself, and comes about neither through objectifiable criteria nor through the evaluation of the researcher himself. Instead, the researcher or investigator here is the individual himself or herself, looking at him or herself.

The larger area of scientific research in the inner, individual realm wants to make the nonvisible visible, graspable for research in some form, and thus mostly makes use of an external perspective on the inner experience of the individual holon. This area of research Wilber calls Zone 2 and assigns structuralism to it as a proxy methodology. "When you research them [these realities], you are looking at them "from without," you are not necessarily experiencing them from within." (Wilber 2006a, 54). Internal processes and operations of the individual, such as value orientation, religious orientation, emotional development, etc., are thereby assigned by the researcher (or the subject observing him/herself from the outside) to certain structures that contain different levels of manifestations of the respective process. Typical structuralist approaches exploring this quadrant include Kegan's work on consciousness development (Wilber, 2006a), Gilligan's approach to female morality (Wilber, 2000), and Graves' Spiral Dynamics model of individuals' value development (Beck & Cowan, 2008, cf. Section 3.1.3). It is also the zone that is invoked as an example of developmental lines in many of Wilber's works (2000, 2006a, 2009). Explored are the structures that individuals follow in certain internal phenomena, "one describes what invisible rules are obeyed by the phenomena that show themselves as phenomena to consciousness as 'immediately given'" (Wittrock, 2008, 51). In Zone 2, simply put, researchers assign an individual's inner experiences to particular levels of a structural model.

3.2.2.2 Methodologies of the inner-collective dimension

From the inner-individual aspects, the model turns to the inner-collective aspects of a holon with zone 3, which is about the scientific consideration of the inner perspective of the inner experience of a collective holon. Hermeneutics is named as the guiding methodology of this zone, which is concerned with describing the 'felt we', the space of intersubjectivity. "But the subject matter is this actual we of understanding." (Wilber, 2006a, 157). Intersubjectivity, that is the emotions, thoughts, insights, and values shared by a group, or at least the vast majority of its members, where a single individual could never feel this 'we', could not have these experiences, without the fellow members of his group. As a researcher one takes part in the inner experiences of the group and has to understand the experiences in a hermeneutic circle, because only from the inside the 'we' can be grasped.

But from the inside, that we is a felt meaning, a conglomerate of signifieds, not a syntax but a semantics, not a structure but a yearning, not a grammar but a space of shared feelings and visions and desires and conflicts, a vortex of love and disappointment, obligations and broken promises, mutual understanding and devastating betrayals, the ups and downs of almost everything you call "important" in life, these webs of felt relationships (Wilber, 2006a, 156)

The external view of the internal experiences of a collective holon is the subject of Zone 4, for which Wilber cites ethnomethodology as an exemplary methodology. "Ethnomethodological research provides precise descriptions of the methods used by members of a society, group, or community to do whatever it is they do." (de:Wikipedia, Ethnomethodology). Wilber (2006a) further cites archaeology, genealogy, cultural anthropology, post-structuralism, and semiotics as examples. All fields and methodologies aim to capture and systematize the 'felt we' in namable categories and structures (grammar, syntax, etc.).

A more obvious and mundane example is ethnomethodology, which deals with the underlying codes, conventions, and rules of social interactions, and which is listed [...] as representive of zone #4, as long as it is understood that all sentient beings, not just humans, have an ethnos or ocial grouping. (Wilber, 2006a, 155)

To the 'we' from an external perspective, Wilber ascribes the status of something difficult to see, something that is mostly grasped only in terms and categories of a 'they', that is, from an external collective perspective, but which ignores the internal components, the 'felt we'.

The inside of a we can be felt, but the outside of a we has to be seen from a distance, and then over time, in order to grasp its full significance and structure. (Wilber, 2006a, 161f.)

Describing intersubjectivity from the outside requires the researcher to participate in the group itself, to experience the inside perspective of the we, in order to then describe the patterns of interaction in terms of categories and structures from the outside.

3.2.2.3 Methodologies of the external-individual dimension

The interest of the sciences assigned to the right-hand side in the quadrant model lies in observable processes and objective data, whose fascination, in Wilbers opinion, is particularly due to the simplicity of the assumptions associated with them.

I see sensorimotor objects out there; those objects (and probably those objects alone) are real; therefore true knowing consists of following the behavior of those objects as carefully as I can: that is, true knowing consists of making an accurate map of a pregiven nature. (Wilber, 2006c)

In the upper right quadrant, zone 5 describes the external phenomena of an individual holon from the internal view. As a representative methodology, Wilber mostly mentions autopoiesis according to Maturana and Varela (1987), which attempts to describe from an organism's inside how it develops or generates itself.

This form of scientific knowledge is clearly different from the prevailing empirical methodology of Zone 6, which describes from the outside, and forces the researcher to adopt a quasi 'organic-empathic' attitude without having a dialogical access to the object of research.

This is the fundamental difference between classical behaviorism and autopoietic behaviorism. The former looks at the objective organism from without (zone #6), the latter, from within (zone #5). (Wilber, 2006a, 170)

The world of the holon under investigation is no longer described from the conceptualisations of the surrounding system (which is represented by the scientist), but an attempt is made to reconstruct the holon's world view from the organic circumstances (many olfactory cells in an animal species indicate an olfactory world enactment, i.e., a reconstruction of a world that consists more of olfactory signal stimuli than of visual signal stimuli).

Note that here, too, it is assumed that the biological organism 'stages' its world as an autopoietic system, i.e., it does not simply take in 'the world' via the senses, but co-creates the experience of its specific surrounding world. (Wittrock 2008, 57)

Other methodologies in this zone are, for example, sociobiology or neurophenomenology, in which the activity in certain brain areas is used to infer certain experiential contents without the subject himself being questioned.

In Zone 6, also located in the upper right quadrant, empiricism is the predominant methodology, which explores the external phenomena of an individual holon from an external

perspective. This perspective dominates the current scientific landscape, which is critically noted by Wilber (2006a). This influential area of research is important according to integral understanding, but its importance is overestimated by the traditional science establishment, Wilber (1997, 21f) speaks of flatland reductionism, which reduces cognition to the perspective of the third person, the 'it' (or 'they') and ignores the perspective of the first person. In the field of consciousness research, scientific fields in this quadrant include neuroscience, which uses magnetic resonance imaging and positron emission tomography to investigate the structure and states of the brain (Wilber, 2006a), but also physics, chemistry and biology.

3.2.2.4 Methodologies of the exterior-collective dimension

The area of exterior-collective phenomena, bottom right, is devoted to patterns between objects (Wittrock, 2008) in contrast to the patterns between subjects observed in the lower left quadrant (zones 3 and 4). The lower right quadrant is first represented by zone 7, which reflects the interior perspective on the external processes of a collective holon. Wilber cites Luhmann's social autopoiesis, "the view from within" the social system (Wilber 2006a, 174), as the central methodology, whereby primarily the interactions between the individual holons of a social holon are considered in their development from within themselves. "The transfer of the concept of autopoiesis [by Maturana and Varela, 1987, cf. ch. 3.2.2.3, B.W.] to the phenomenal field of the social has the consequence that social entities are described as closed operating units that generate and maintain themselves by means of the recursive production of their elements." (Kneer & Nassehi, 1993, 65). According to Luhmann's understanding (Kneer & Nassehi, 1993), possibilities of intervention on the system from the outside are thus extremely limited. Science in this understanding does not so much look for ways of influencing the system, but rather gives a description of the mechanisms of selfpreservation even under environmental influences, also with the background of showing risks and dangers of (self-referential) development.

Zone 8, the external view of the exterior phenomena of a collective or social holon, is finally the research sector of classical systems theory. Here, the structures and manifestations of the interactions of individuals are described from the outside, from an objectifiable point of view, in terms of their relevance to the system. "A social (LR) holon is composed of its members plus their exchanged artifacts." (Wilber, 2006a, 174). The focus of scientific interest is on processes, control loops (cybernetics), functions and structures that are necessary for system maintenance or system change (Miller, 1999). The individual is only relevant in its functionality and fit into the system. Integral Theory, for example, names chaos theory as a representative of this zone (Wilber, 2006a), which can be supplemented by the various systems theory approaches in economics and the social sciences.

3.2.3 The three strands of knowledge

The so-called three strands of knowledge are the steps of injunction, apprehension and confirmation familiar to all established sciences (Wilber, 2001a, 90), which are valid for

science in all four quadrants. The scientific process of knowledge always begins with an instruction, a prescription, the injunction, as to how the data collection is to proceed. Types and forms of experimentation diverge: For the comparison of meditation experiences, there must be agreement on the procedure regarding meditation practice, framework conditions and others. For testing the effectiveness of medicines or other substances, standardised test series must be carried out. For the observation of culturally specific behaviours of people with dementia, field research must be conducted according to defined procedures. And for the comparison of health care systems, certain data must be collected in defined contexts after prior planning. Each zone has its own methodological specifications that determine the type and implementation of injunction, data processing and verification.

Perception takes place through data collection in the experiment, which can also consist of self-observation in the upper left quadrant in accordance with the injunction. These data can be of different natures according to the overarching methodology (zone). "All good science - narrow or broad - is to some extent anchored in data or experienced evidence." (Wilber, 2001a, 90). The rules of the epistemological path, whose injunction is determinative of the data, also apply to the processing of the data obtained (Wilber, 2001a).

The final step is verification, which involves refutation or confirmation of the initial thesis. Through the injunction, the basic procedure of gaining knowledge is repeatable and verifiable for all to a certain extent.

A community of peers—or those who have adequately completed the first two strands (injunction and data)—is perhaps the best check possible, and all good science tends to turn to a community of the adequate for confirmation or rejection. (Wilber, 2001a, 75)

If this is transferred to practical research areas, deviations are to be expected here: While a simple memory test with prepared test material is relatively easy for most users to perform, meaning that the injunction can be followed by as large a group as possible, this is more difficult in studies on meditation practice, which is based on highly individual mechanisms that can hardly be influenced from the outside. However, since there are also different validity claims for all four areas of effect, it ultimately makes no difference whether data are obtained from a memory test or a meditation experience, as long as they do justice to the validity claim of the respective quadrant.

Thus, the three strands of knowledge apply to science in all quadrants with their corresponding validity claims. Strictly speaking, the three strands must also take into account the different levels of development, for example of the researchers involved, the surrounding system or similar. The application of the injunction by a meditation novice will yield different results than that of a Zen master (levels of development), people with a highly developed cognitive and moral development lineage may evaluate interviews on moral

judgements differently than cognitively less developed persons (lines), men and women may have different perceptions when applying an experiment and come to different results due to different contexts of experience (types) and finally the states must also be taken into account in an integral path of cognition: In which state did the observance of the injunction occur? In meditative contemplation, in a dream or in a waking state?

To be considered in the three-step approach of integral research are the three principles of Integral Methodological Pluralism (Wilber, 2006b). Non-exclusion means the fundamental willingness to recognise in every contribution a relevance to the issue being researched, even if it may be very small ("no human mind can produce 100 % error", Wilber, 2006b, 22). Unfolding is understood as taking into account the holarchical principle of inclusion and transcendence also in the generation of new knowledge, which also means questioning old paradigms and allowing for new ones (Wittrock, 2008). Finally, integral research requires attention to precise staging, i.e. attention to injunctions, to the specifications of the respective methodology, so that within its validity claim the corresponding data can be reproduced (Wilber, 2006b).

3.3 Summary: Integral research

In summary, Integral Theory demands that an integral research process includes as many structural elements as possible in the scientific process.

The injunction of integral methodological pluralism requires the orientation of the object of knowledge to the structures of the quadrants (ch. 3.1.1) or dimensions, whereby different validity claims must be taken into account. A consideration of the respective external and internal view with their different ways of cognition (ch. 3.2.2) complements this orientation. The injunction also demands that the object of knowledge be differentiated according to the various lines (ch. 3.1.2) in which development takes place across different levels. The characteristics of development on the different levels (ch. 3.1.3) of the respective lines must also be presented. Finally, the integral approach requires to take into account the different typical (ch. 3.1.4) and temporally limited states (ch. 3.1.5) of development.

Linking all these aspects and showing cross-connections as transparently as possible is what scientific work with the integral approach is all about. The principle applies that first of all no findings are to be excluded (non-exclusion, cf. ch. 3.2.3); furthermore, the willingness to question traditional methods and paradigms in order to be able to generate new knowledge (unfolding, cf. ch. 3.2.3) is a prerequisite for integral research. The ways of obtaining data using different methods (perception, cf. ch. 3.2.3) must be designed in such a way that verification is possible as the final step of the research process.

Based on this theoretical approach, the following chapter discusses basic concepts and assumptions that are relevant for an application of Integral Theory to dementia.

4 Key assumptions for an integral dementia concept

In the previous chapters it became obvious that there is a lack of comprehensive dementia concepts (cf. ch. 2.2), combined with a dominance of the dementia discussion by the medical-behavioral sciences (cf. ch. 2.1). This dominance is increasingly criticized by various groups, by experts (Whitehouse & George, 2009; Wissmann & Gronemeyer, 2008), but also by some persons affected by dementia (Taylor, 2008).

There is a multiplicity of diagnoses, criteria, forms of therapy, approaches to care, and opinions, with no validated evidence to date on the causes of dementia (Wissmann & Gronemeyer, 2008). A significant use of cross-connections and synergies of different findings seems to be tedious up to almost impossible. This confusion of data resulted in the basic assumption that led to the topic of this thesis: So far, there are few dementia concepts whose framework is broad enough to link as many different findings on dementia as possible in a meaningful way and to clarify their interrelationships in a structured way. There is a lack of an overview, a metatheory in the sense of an overarching theory that brings together the existing findings.

Furthermore, it was shown above that the integral theory offers a framework to describe an issue comprehensively from a scientific point of view, taking into account previously conflicting viewpoints (cf. ch. 3).

The essential hypothesis of this thesis is that the Integral Theory is suitable to develop an integral dementia concept based on its structural elements and specifications of the Integral Methodological Pluralism, which is so comprehensive that a large number of findings on the entity dementia can be linked and integrated within the conceptual framework. Therefore, the aim is to create a draft for an integral dementia concept that provides a basic framework for a description of dementia according to integral criteria.

Viewing dementia from an integral point of view follows the claim of what Integral Theory wants to be: a 'theory of everything' (Theory of Everything, Wilber, 2001a). If one takes this claim seriously, it is consistent to confront the Integral Theory with the challenge of not only being able to describe a forward-upward development of consciousness, but also the phenomenon of an apparently regressing consciousness on the basis of its structural elements. This will also be the special challenge of this thesis: To transfer a phenomenon of consciousness, which has or seems to have the regression of (cognitive) consciousness as a special feature, into an approach, which so far has mostly been characterized by working on the development of higher levels of consciousness (Wilber, 2006a).

However, before an integral dementia concept can be outlined on the basis of insights from the theory and practice of dementia care and dementia research, it is first necessary to draw the necessary consequences from integral claims and to examine which basic requirements an integral dementia concept must meet.

4.1. Holon dementia

Before applying the integral model to dementia, it must be clarified whether dementia is at all suited for an integral consideration, as one of its basic assumptions is that evolution always contains an increasing complexity of the entities concerned (cf. chapter 3.1). At first the concepts of dementia and evolution seem to exclude each other, since according to the predominant understanding of dementia there is always a regression in the context of this phenomenon: A regression of the cognitive abilities of people with dementia (Engel, Mück & Lang, 2009), increasingly also of their involvement and participation in society (Wißmann & Gronemeyer, 2008), and organically a regression of their neurons and brain (Holthoff, 2009). Even integral theorists assign people with dementia in the last stage to the lowest stage in their developmental model (Beck & Cowan, 2008; Wilber, 2001a). Simplification rather than increasing complexity seems to prevail here. How, then, can one describe a phenomenon seemingly contrary to the evolutionary principle with a theoretical approach that sees forward-upward evolution as the basic condition of its approach?

A first answer is given by a basic assumption of the integral approach, as formulated by Weinreich (2005) in his approach to an integral psychotherapy: "The integration of contradictory aspects of a level can only happen at any time from a higher level of development." (Weinreich, 2005, 28). Dementia is of a sort contradictory: regression (in the form of a neurodegenerative disease) happens in an environment characterized by development (in the form of increasing individual awareness as well as growing level of medical-neuroscientific research), without the causes of regression being really fathomed so far (Wißmann & Gronemeyer, 2008). Resolving this inconsistency of dementia will perhaps only be possible at a higher level of development that incorporates and transcends all current knowledge. Development toward greater complexity and depth, as is suggested by the integral approach, is therefore necessary in all areas to address the phenomenon of dementia.

Crucial for the relevance of dementia for an integral approach ultimately remains the fact that dementia is a process that also (but not only) takes place in a conscious, feeling person - in his body, in his consciousness, in his relationships and in his environment. The affected people remain people in the sense of independent persons until the end, even if there are ethically different limiting views about this (Wetzstein, 2005b). Thus, they are and remain holons, which are wholes and parts. Thus, dementia is a part of human evolution and human consciousness and can therefore be considered a holon.

However, dementia as a unique phenomenon can also be considered as a holon, if the focus is not on the 'disease' or dementia-related changes in an individual person, but on the phenomenon itself. Here, the focus is on dementia-related change, on what constitutes dementia and what is changed by dementia at each level (cf. Mahlberg & Gutzmann 2009a, among others, for the individual points):

- the single neuron that dies,
- which is part of a brain area whose functionality is increasingly limited and which eventually regresses,
- which is part of an individual that increasingly loses memory and much more due to these increasing changes,
- which in turn is part of a society that is constrained by that member's failure, social withdrawal, and need for care (where there is a shift here from the individual dimension to the collective dimension, which are "equivalent (but not identical) dimensions of each occasion." (Wilber, 2006a, 145)

4.2 Focus of this thesis

So, what is the holon to be considered? This is where the first challenge of the integral model becomes apparent, to provide a sufficiently deep framework for the complexity of a (supposed) disease such as dementia that can encompass all facets equally. If one sticks to the medical definition of the term, it is possible to focus on a single form of dementia, which, as shown in Figure 10, would be represented in the quadrants as follows:

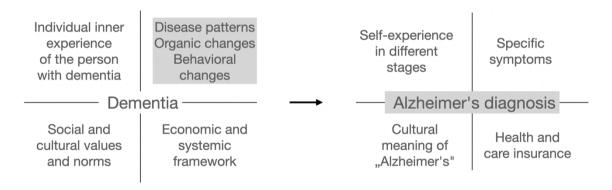


Fig. 10: Aspects of the exterior-individual quadrant as an independent holon¹

If, on the other hand, the focus is placed on the individual person with dementia as a holon, the relevant aspects in the quadrants shown in Figure 11 arise:

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¹ This and all following figures in this paper are the author's own illustrations.

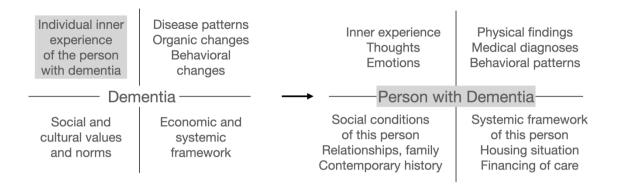


Figure 11: Aspects of the interior-individual quadrant as an independent holon

However, with the approaches shown in Figures 10 and 11, one remains caught up in individual aspects of the phenomenon of dementia, in the first case placing a medical diagnosis of the upper right quadrant, and in the second case focusing on the patient in his or her individual as well as social relations. A further focus would be the consideration of dementia in a religious community (as an aspect of the interior-collective quadrant, cf. Fig. 12) or in the system of old people's homes (as an aspect of the exterior-collective quadrant, cf. Fig. 13).

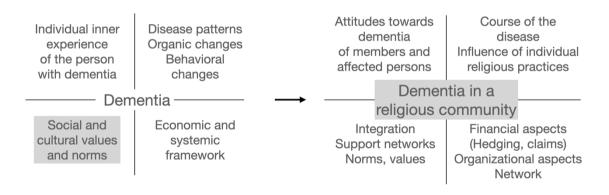


Fig. 12: Aspects of the interior-collective quadrant as an independent holon

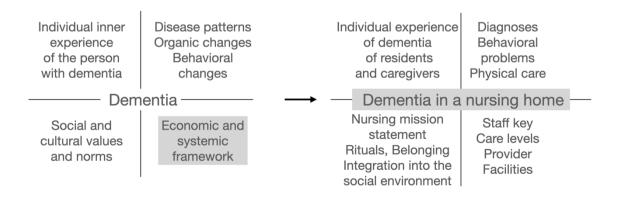


Fig. 13: Aspects of the exterior-collective quadrant as a holon.

However, the aim of this thesis is a dementia concept that is more far-reaching and offers space for many other aspects of dementia: semantic meaning, cultural reception, personal experience of people with dementia, subjective external perception of relatives, organic development and medical diagnoses, insurance law and financial significance, ethical relevance and political positions, pharmacological therapies or nursing care concepts. Therefore, a comprehensive and at the same time delimited term of dementia must be defined as the basis of this concept.

4.3 Terminology

Dementia is seen in this work as a phenomenon around the clinical pictures of dementia as defined by the ICD-10 of the WHO (DIMDI, 2010) in all its cultural, systemic-organisational, individual and organic references. For this thesis, dementia is explicitly not defined as a disease, but as a term currently attributed to certain organic changes and behaviours of affected people associated with the ICD-10 criteria.

The definition of dementia in the ICD-10 is the basis of many standard works on dementia (Förstl, 2009a; Mahlberg & Gutzmann, 2009b), research projects and publications. It can currently be regarded as the only globally valid definition of the entity dementia, whose criteria, however, no longer correspond to the latest state of research (for discussion, see WHO, 2007). However, since the new edition as ICD-11, which is in preparation, is not yet known, this version will be the definitional basis of this work.

Dementia (F00-F03) is a syndrome resulting from a mostly chronic or progressive disease of the brain with disturbance of many higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning ability, language and judgement. Consciousness is not impaired. The cognitive impairments are usually accompanied by changes in emotional control, social behaviour or motivation, occasionally these also tend to occur. [...] (DIMDI, 2010)

From an integral perspective, it must be taken into account that in this case individual interior as well as exterior processes are defined by an institution with worldwide influence, so the consideration must take into account the exterior-collective influence. Dementia is defined by a system that is based on knowledge from experts representing perspectives from all quadrants but is nevertheless always also subject to institutional constraints. In the case of WHO as a 'defining power', it should also be kept in mind that the institution is obliged to represent the interests and concerns of all people involved (Wetzstein, 2005a), and therefore, for reasons of validity of the definition for as many nations involved as possible, will always remain somewhat more general in its definition than a nationally oriented and more research-focused association (Wetzstein, 2005a) such as the American Psychiatric Association (APA).

Here the validity claim of the exterior-collective quadrant, the functional fit, becomes clear: a globally valid dementia definition must be sufficiently open that it is functional for all health systems involved. The dementia criteria of the APA's DSM-IV are more nuanced in this respect, since, as a primarily nationally oriented organisation, they can refer to a more restricted (though still culturally broad) group of people. Especially because of the worldwide validity of the ICD-10 criteria, these will be the basis of the work here.

A further literal definition of the term dementia will be omitted here, since any definitional approach already implies a determination of the focus of a certain path of knowledge. Through the ICD-10 definition, a pre-determination of a medical definition is already made; however, this contradiction cannot be resolved for the time being and thus the demand on the research process arises to consider this fact sensitively.

So far in this work, the term phenomenon has mostly been used as a description for dementia, but this also needs to be concretised in the sense of a precise meaning of the word: In this work, dementia is considered both in its appearance as a phenomenon and as a noumenon, i.e. both as the event accessible to sensory perception (de:Wikipedia, Phenomenon) and as the thought itself, the "to be known with the mind" (de:Wikipedia, Noumenon) in Plato's sense. In this way, both the right-sided (phenomenon) and the left-sided (noumenon) ways of cognition are taken into account in relation to the quadrant model. The entity in the philosophical understanding of the term, which is defined as "unspecified existence of something" (de:Wikipedia, Entität), is chosen here as the overarching concept. Understanding dementia as an entity therefore means recognising it as 'something that exists' without being able to determine its nature. Such an open definition makes it possible to break away from previous definitions and to really openly include all aspects, the measurable as well as the conceivable.

The term quadrant or dimension, which Wilber usually uses synonymously (cf. ch. 3.1.1), also needs to be clarified. In connection with the entity of dementia, the dimensions of dementia appear to be the linguistically more intuitive terminology than the quadrants of dementia. Therefore, in the further course of this work, the term dimension is usually preferred to the term quadrant.

Finally, a closer look at the term concept is still pending, which should characterise the content and outcome of this work. The term dementia concept is chosen with reference to Wetzstein (2005a), in whose study the term was (re)introduced into the dementia discussion. In her study, she gives an overview of the substantive precursors of the dementia concept (Wetzstein, 2005a), but does not define the character and extent of a concept. There are also hardly any in-depth definitions to be found in the encyclopaedic literature. Meyer's Großes Taschenlexikon (1992) defines it as a "[keyword-like] draft, first version of a speech or writing, plan"; in Wikipedia, concept is described, among other things, as a 'first draft or as a preliminary stage of a theory' (de:Wikipedia, Konzept). Finally, the Deutsche

Wortschatz [German Vocabulary] of the University of Leipzig (Deutscher Wortschatz, 2011) offers as a synonym, among others, model of thought.

If one summarises these definitions and synonyms and transfers them to the framework at hand here, a dementia concept can be defined as a thought model as a preliminary stage of a theory. An integral dementia concept is therefore understood in this work as a model of thinking about the entity of dementia based on Integral Theory.

Based on the explanations of the terms, the following section now presents the epistemological research framework of this thesis.

4.4 Epistemological research framework

According to an integral understanding (cf. ch. 3), all ways of knowledge that can be assigned to one of the four quadrants and that have a stake in the description and research of the entity of dementia are admitted in this work. The aim of an integral dementia concept is also the integration of different areas of knowledge, so that not only scientific research results, but also the knowledge of non-scientific professions, representatives of relatives and above all the people with dementia themselves, furthermore, for example, media contributions of different kinds (literature, films, websites) and experiences of different groups of people with dementia are to be included. Relevant for the inclusion of the findings and results of a person, group or institution involved is first of all not the scientific quality, but the question of whether the findings meet the validity claim (ch. 3.2.1) of the respective quadrant. The ideal of an integral dementia concept would thus be an overall picture of the entity of dementia that includes all currents and appreciates the shares of each contribution.

In order to test the thesis of the suitability of Integral Theory as a model for an integral dementia concept stated at the beginning of the chapter, two steps are taken. In a first step, an integral dementia concept is to be developed in its basic features, which is then to be tested in a second step for its scope in the sense of openness to as many insights into dementia as possible. The methodological details of both steps will be explained in more detail below.

4.4.1 Procedure for the development of an integral dementia concept

In the first step of the theoretical development and review of an integral dementia concept, a blueprint for an integral dementia concept will be developed in chapter 5 from the basic principles presented in the preceding chapters. For the first section of the methodology, criteria for a dementia concept based on the integral approach are formulated below, considering the implications of an integral methodological pluralism (ch. 3.2).

1. An integral dementia concept should bring together findings on the entity of dementia from the relevant methodologies/zones from all quadrants of the Integral

- Theory (cf. ch. 3). Where possible, the interconnectedness of these four perspectives should be shown.
- 2. An integral dementia concept should include relevant lines, levels, types and states of dementia in all quadrants as comprehensively as possible.
- 3. An integral dementia concept should also include not only the entity of dementia itself, but also the perspective of as many stakeholders as possible (people with dementia, relatives, caregivers, researchers).

For the development of an integral model of thought or an integral concept, the following questions, which arise from the implications of the structural elements and the Integral Methodological Pluralism, offer clues for the scientific approach:

- What are the subject areas in this quadrant?
- Which scientific fields, disciplines, professions and institutions have their focus in the epistemological pathways of this quadrant?
- Which lines are differentiated in this dimension? How is this done?
- What other lines are thinkable in this quadrant?
- Which levels show up in this quadrants?
- Which levels can be relevant beyond this? What connections can be possible to other lines and levels?
- Which typologies can be found in this areaa?
- Which typologies are further conceivable in this area?
- · Which states are considered by the respective methodologies?
- Which states are still possible in this quadrant and have not yet been considered?
- What correlations with other areas are evident in the respective quadrant?

For the design of an integral dementia concept, the questions regarding the quadrants and lines in particular provide the orienting framework. The spectrum of an integral view of dementia will be shown exemplarily on some lines of each quadrant and substantiated by data material from dementia research. For this purpose, online accessible sources from the databases GeroLit and Medline, some basic works of the current dementia literature (e.g. Förstl, 2009; Mahlberg & Gutzmann, 2009) and sources from the publications of the Kuratorium Deutsche Altenhilfe and the Demenz Support Stuttgart will be used to a large extent.

The integral approach with its multi-layered structural elements bears the danger of losing the common thread in the diversity of perspectives, lines and levels. Therefore, this work will be guided by the following ranking of structural elements:

- Quadrants as the top structural element,
- A number of exemplary lines as areas of development within the quadrants,
- Overview of some levels, states and typologies,
- Overview of zones as areas of different methodologies

The focus of this paper is thus within the quadrants on the exemplary presentation of some lines of development of the entity dementia. Individual examples of levels, typologies and states are added. The presentation of a possible relevance of the zones concentrates on an orienting overview.

Subsequently, dementia is largely considered in the cultural and systemic structures of the Federal Republic of Germany. A few examples from Scotland or the USA complement this, if there are no equivalent findings or structures in the German-speaking world or scientific field. Additional differentiation according to different cultural and systemic aspects (insofar as they transcend cultural diversity within Germany) is dispensed with here.

4.4.2 Procedure for reviewing an integral dementia concept

The thesis that an integral dementia concept provides the theoretical framework for incorporating a wide range of knowledge about dementia into its structure as comprehensively as possible will be examined in chapter 6.

For this purpose, the data of a sample of publications on dementia from a scientific data-base will be categorised and evaluated with the help of a literature analysis. The categories will be formed using the structural model of the quadrants of Integral Theory, based on the insights gained in chapter 5 about the basic structures of an integral dementia concept. The thesis linked to the main thesis of this thesis, that an integral dementia concept offers a range with which different insights into dementia can be included and linked as comprehensively as possible, is to be examined. Methodologically, this scope will be tested by examining in detail whether each publication of any sample of dementia literature can be assigned to at least one dimension of an integral dementia concept.

It will also be examined which relations become visible between the data obtained in the respective quadrants and whether the dominance of medicine over the dementia discussion discussed in chapter 2 and claimed by various authors (Wetzstein, 2005; Wißmann & Gronemeyer, 2008) can be represented with the help of the integral model.

The following chapter, however, is first dedicated to the development of an outline for an integral dementia concept.

5 Draft for an Integral Dementia Concept

In this chapter, a draft for an integral dementia concept will be sketched on the basis of the Integral Theory presented in chapter 3 and on the basis of the essential assumptions and methodological procedures described in chapter 4.

If all fields of science have their equal share in explaining reality (cf. ch. 3.2), then an integral dementia concept must offer the theoretical space to integrate all the sciences and approaches involved and to place them on an equal footing. If one wants to represent dementia in all dimensions and perspectives, it is necessary - as shown above - not to focus on individual aspects of dementia, but on the entity itself.

For the respective quadrants, the leading sciences listed in Figure 14 can be identified as an overview.

| | INTERIOR | EXTERIOR |
|------------|--|---|
| INIVIDUAL | Psychology Gerontology Nursing Science | Medicine Geriatrics Pharmacology Gerontopsychiatry |
| COLLECTIVE | Sociology Ethics Religious Studies | Economics Political Science Public Health |

Fig. 14: Some of the sciences involved in the respective quadrant.

In the following, the consideration of the entity dementia runs along the sequence from the upper left to the upper right quadrant, then from the lower left to the lower right quadrant, i.e., from the individual to the collective aspects of dementia.

5.1 Interior-individual dimension of dementia

In the interior-individual quadrant, data is obtained from the inner experience of individuals, using multiple ways of knowing such as "meditation and contemplation, introspective psychology, psychoanalytic endeavours, shamanic journeys, the phenomenology of attention, dream analysis and bodywork" (Wilber, 2006c, 191). Knowledge about the interior-individual perspective of dementia is generated by psychology and gerontology, but also by geriatric care and caregivers themselves, increasingly supplemented by autobiographical accounts of people with dementia as well as relatives.

The interior-individual quadrant is about the experience of dementia from the inside with the validity claim of truthfulness (cf. ch. 3.2.3). Which feelings does a person with dementia have and how do these change in the course of the disease? What thoughts do people have

about dementia? How do self-image and perception change in the course of dementia, of people directly affected, but also of accompanying relatives? What feelings do companions and other people involved, doctors, carers, neighbours, but also politicians who make health policy decisions, have about dementia? Dementia also 'exists' in them in the form of thoughts, fears, hopes and values. These perspectives of dementia are no less relevant, because they decisively shape the way dementia is dealt with and thus also the self-experience, thoughts and feelings of the people with dementia themselves (Kruse 2010).

Excursus: Thought, considered integrally

According to Wilber (1997), thought itself is an inner process, a process of the mind or consciousness that is part of a person's inner awareness, but not an empirically observable process. What can be empirically recorded are the neurophysiological correlates, brain wave patterns, certain metabolic activities and behaviours, from changes in physiognomy to increases in blood pressure to concrete activities that can occur in conjunction with a thought.

We might eventually find that they are indeed two different aspects of the same thing, or that they are parallel, or dualist, or interactionist, or whatever, but the crucial point for now is that, in any case, neither can be reduced to other without remainder, because whatever else might be said, they each have a drastically different phenomenology. (Wilber, 1997, 10f.)

However, the collective quadrants are also involved in shaping the content of the individual thought, in that each thought of an individual is based on a horizon of experience that is shaped both by the surrounding society (inner-collective) and by the system (outer-collective) of which it is a part. An overview of the possible influences of each quadrant on the inner-individual process of *thought* is shown in Figure 15. The different perspectives are thus separate, but nevertheless interwoven: An inner-individual process must be seen and examined from its perspective (validity claim), but it is constantly subject to influences from the other quadrants and is thus ultimately a product of all quadrants (Wilber, 1997).

Now the point of this overall example is simply that my "single" thought, the original holon, is not really a single thought as such, but rather a holon with four inseparable aspects (intentional, behavioral, cultural, and social), each with its own validity claims (subjective truthfulness, objective truth, intersubjective justness, and interobjective functional fit). (Wilber, 2000, 145)

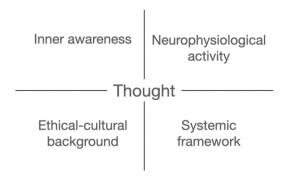


Abb. 15: Thought, considered integrally

A differentiated consideration of *thought* as part of cognition in the context of the entity dementia is therefore advisable but can only be considered in a rudimentary way in this work. The assumption for this work is that the thought itself is an event in the inner-collective quadrant, which has correlates in all other quadrants (Wilber, 1997, 2006a).

The next section now provides an orientation on the dementia-relevant lines of the inner-individual quadrant.

5.1.1 Lines

This section describes the areas, the lines, where development takes place within the inner-individual dimension of dementia. Since the lines of this quadrant are theoretically well founded in Integral Theory (Wilber, 1997, 2000, 2006a), and since it is assumed that the areas of inner-individual consciousness do not differ fundamentally but only gradually under the influence of dementia changes, the guidelines of Integral Theory in this area can be used for an integral dementia concept.

Some lines of an interior-individual development, as outlined by Wilber in his various works (2001a, 2006a), are used as an orientation standard. Lines here symbolise the different areas of development of an individual in the inner realm (cf. ch. 3.1.2), which are deliberately not reduced to people with dementia, but also consider the perspectives of as many people involved as possible. Figure 16 shows examples of some lines of the Integral Theory that can also be relevant for the entity of dementia in the inner-individual realm.

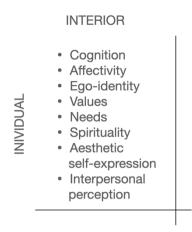


Fig. 16: Some lines of the interior-individual dimension of dementia

If the lines mentioned in figure 16 are applied to dementia, the following exemplary aspects of an integral dementia concept emerge:

The **cognitive line** asks how the respective person perceives what dementia is. What does the person perceive, what does he/she know about dementia, what are his/her thoughts about it? Findings on this line are available, among others, from research on the insight into illness of people with dementia (Engel, 2011), the insight and level of knowledge of spouses (Franke, 2005) or from research on "the phenomenon of 'professional resistance' to early diagnosis" (Pentzek, Fuchs & Abholz, 2005, 502) of GPs.

The **affective line** asks about the emotions regarding dementia. Among other things, autobiographical data from affected persons (Taylor, 2008; Zimmermann, 2009) and data from interview studies with affected persons (Engel, 2011) are available for this. For people in an advanced stage of dementia, the assessment instrument H.I.L.D.E. (Becker, Kruse, Schröder & Seidl, 2005) is a method for data collection. The emotional situation of relatives must also be taken into account (Engel, 2008).

For **the line of ego identity** with the question of understanding one's own self under the influence of dementia, insights arise from autobiographical testimonies (Taylor, 2008), but under certain circumstances also from the approaches of pre-therapy, whose aim is to enable severely dementia-modified people "to relate to themselves [...] again." (Pfeifer-Schaupp, 2009, 336).

For the **line of value orientation**, the Spiral Dynamics model is often used in Integral Theory (Wilber, 2001, 2006a). The relevance for dementia is shown in the exemplary naming of people with dementia for the lowest level of this developmental model (Beck & Cowan, 2008, Wilber, 2001a). However, the transfer of the orientation-providing value patterns of this model to people with dementia and other persons involved in dementia is still pending.

For the **line of needs**, Maslow's model of the pyramid of needs is mostly used (Wilber, 2006a). Data on the relevance of the levels of needs can be found in Höwler (2008) for relatives and companions of people with dementia. Kitwood's needs model (Kaufmann, 2010) is particularly suitable for assessing the needs of people with dementia.

The **spiritual line** asks about the spiritual needs of people with dementia (Müller-Hergl, 2007) or also of relatives (Radzey, 2007). The Spiral Dynamics model may also be relevant here, offering explanatory approaches to the spiritual needs of people with severe dementia (Küstenmacher, Haberer & Küstenmacher, 2011).

The **line of aesthetic** self-expression has to take into account, among other things, the aesthetic expressions of persons affected in their processing of dementia. Zimmermann (Quarks & Co, 2010), a person affected by dementia who discovered painting as a form of expression for himself, museum visits by people with dementia (Jonas, 2009) and the creative phases of well-known artists such as Willem de Kooning (Shenk, 2005), who also continued their artistic activity under the influence of a dementia-related change - these examples stand for aspects of an aesthetic dimension of dementia from within.

In the area of **the interpersonal line** of development, the focus is on one's own perception of interpersonal aspects under the influence of dementia. Sterin (2002) gives some indications of how dementia can express itself internally-individually on the interpersonal line for people with dementia. Kruse (2010) points out that a negatively or stressfully toned attitude of a person towards a 'dementia patient' can turn out to be a massive disturbance in communication, which the person with severe dementia also clearly feels.

5.1.2 Levels, states and typologies

For some of the lines mentioned above, levels can be identified that represent development over time in this area. Thus, for the lines of moral development according to Maslow (cf. Wilber, 2006a) and value orientation (Beck & Cowan, 2008), development over different levels is already implied. For the cognitive line, using the example of the insight into the disease [Krankheitseinsicht] of people with dementia, a development over time can be observed, which can extend from an awareness that something has changed, to an awareness that changes are 'not normal', to an awareness that the changes are a sign of dementia (Engel, 2011).

The severity of dementia according to ICD-10 (Förstl, 2009b), an objectively verifiable aspect of the external-individual dimension, can also be understood as a model of levels with an impact on the lines in the interior-individual dimension. A dementia process entails that, in contrast to the usual integral descriptions of developmental levels (Esbjörn-Hargens, 2009), no increasing levels of inner-individual depth or exterior-individual complexity are found here, but that with (objectively) increasing severity, a slowing down and deterioration of cognition are described on the basis of various cognitive abilities in the exterior-individual dimension (Förstl, 2009b; Engel, Mück & Lang, 2009). From the finding that "that consciousness develops in direct proportion to an organism's organizational complexity" (McIntosh, 2007, 174), the reverse conclusion can possibly be drawn that the decrease in the complexity of the organism represented by the objective degrees of severity could be associated with a decrease in the complexity of the inner-individual consciousness that can only be verified subjectively. However, no evidence can be presented for this thesis; it is

presented here in the sense of a consideration of connections that have not yet been uncovered, as provided for in the methodology in chapter 4.2.

Exemplary for states in the internal-individual dimension is the state of orientation or disorientation with its four characteristics of time, place, situation and person (Engel, Mück & Lang, 2009), as well as the influence of neuroleptics (Wolter, 2009) and the time of day, e.g. in the sun-downing phenomenon (Mahlberg & Kunz, 2009), each of which can affect the various lines of this dimension, i.e. the various inner-individual abilities of people with dementia as well as other people, in typical ways that are not described in detail here.

In the typologies, the forms of dementia (Mahlberg & Gutzmann, 2009a), gender roles (for physicians cf. Groll, 2008; for carers cf. Neumann, 2009), but possibly also personality types can influence the expression of the respective line or ability.

5.1.3 Inner and outer view of dementia in the interior-individual dimension

Integral Theory distinguishes between two views of the object of investigation, for the interior-individual dimension phenomenology is usually named as the methodology of the inner perspective (Zone 1) and structuralism as the methodology of the exterior perspective (Zone 2) (cf. ch. 3.2.2.1). The methodologies mentioned in Integral Theory as generic terms for the zones (Wilber, 2006a) are followed in the awareness that these only refer generally to the principles of the respective zones (this also applies to the explanations of the zones in the other quadrants that follow later). However, they are considered sufficient for an overview of these zones.

Figure 17 gives an overview of both perspectives of the interior-individual quadrant and possible focal points of knowledge regarding the entity of dementia.

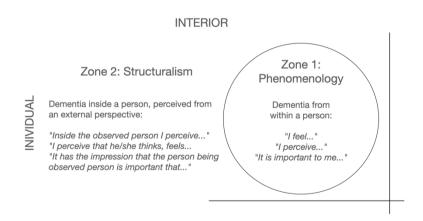


Fig. 17: Possible questions of the zones in the interior-individual quadrant

In the area of **phenomenology (Zone 1)**, the aim is to capture the inner-individual being of dementia from the inner perspective of the individual (cf. ch. 3.2.2.1). Autobiographical accounts of people with dementia (Taylor, 2008), but also of other people from the context of dementia, can be regarded as data. Only a person affected by dementia (directly or

indirectly) can give a true account from introspection of how dementia shows and feels from the inside. Phenomenological insight means that outside researchers or companions can hermeneutically interpret the reports of the person with dementia (who is the actual researcher in the integral sense, in that he produces the data material as a report from his inner experience) as individual testimony, but cannot measure and categorise it according to objective criteria.

The inner-individual dimension of dementia from the external perspective is collected using structuralist methods (Zone 2). The difference to the data of zone 1 is that the (qualitative) data of the subject, e.g. the person with dementia, about the inner experience, perception, moral judgement or aesthetic sensation of dementia are assessed and evaluated or interpreted by outsiders (carers, scientists) or by conscious self-observation on the basis of structures (e.g. categories, patterns, levels) (cf. ch. 3.2.1.2). Kitwood's needs model and its extension by Kaufmann (2010) are examples of structuralist methods in the context of dementia.

In summary, this brief overview of the two perspectives on the internal-individual dimension of dementia shows that the same set of facts (represented by the lines) can be viewed from different perspectives and that, from the point of view of Integral Theory, both perspectives must be given equal consideration, as they each have a part to play in establishing the truth.

5.2 Exterior-individual dimension of dementia

From the inner-individual experience of dementia, the interest now turns to the exterior-individual quadrant. The focus of (scientific) knowledge is dementia as it appears in the physical dimension of an individual: with the organic alterations as well as with the concretely observable behaviours. Most of the epistemological traditions of this quadrant are assigned to Wilber's zone 6, i.e. they look at the external-individual dimension of dementia from an external perspective and describe these processes in objective terms. In addition to medicine, the related neurosciences and the behavioristic psychology, the externally oriented aspects of the nursing sciences, pharmacy, and all related empirical sciences have their share in gaining knowledge for the external-individual domain, whose validity claim is truth (cf. ch. 3.2.1).

In dementia research, medicine is considered the leading science, and the research results from this sector have a high value in the scientific as well as practical consideration of dementia (cf. ch. 2). However, this high regard for the undeniably important medical findings often results in the phenomenon of quadrant absolutism (Wilber, 2007), i.e. the generalisation and overestimation of the data of one field and the associated marginalisation of findings from other epistemological traditions. Many researchers in this field see themselves in a battle against a "scourge of the 20th and 21st centuries" (Haass, 2006, 19), which can only be won through increased use of medical research. With the quadrant

differentiation, Integral Theory gives medicine and its related sciences the space it can define, without this automatically resulting in a definitory influence on the areas of knowledge of the other quadrants.

Questions in this quadrant are: How does dementia manifest itself on an organic level? What processes, what changes can be observed? What kind of behaviours do people with dementia show? What is the specificity of dementia that can be objectively perceived and described? Dementia may also show itself as an entity in physical characteristics or behaviour of companions, relatives and other persons involved. For the description of the basic structures of an integral dementia concept, however, the elaboration will largely concentrate on the external-individual aspects of people directly affected by dementia.

5.2.1 Lines

Integral Theory names the following lines as examples for the external-individual quadrant: organic structures, neuronal systems, neurotransmitters, brainwave patterns, skeletal-muscular growth, nutritional intake and kinaesthetic capacity (Esbjörn-Hargens, 2009, 12). If one asks about the relevance of these lines for dementia, roughly three lines can be distinguished as shown in Figure 18, in which dementia shows up from the objectively perceptible dimension of an individual, here only referring to the objective factors of a person with dementia: In physical/organic characteristics, in abilities and in patterns of behaviour.

Deviating from the integral view of lines, three superordinate lines of dementia are seen in this quadrant, as shown in Figure 18, which can be differentiated into further areas. These are partly to be seen as partial aspects (i.e. 'lines of lines'), partly as level models. The question is whether the organism is to be understood as a level model (molecules - cell - organs - organism) of a single lineage, or as different lineages of bodily development extending over different levels (molecular processes developing at different tempos than cellular structures, which in turn are subject to different mechanisms than the development of different organs). It is answered here in favour of a model of several lines on which development is observed over several levels.

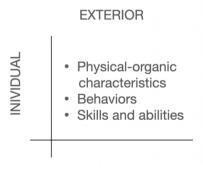


Fig. 18: Some lines of the external-individual dimension of dementia

Numerous data are already available for the **physical and organic line of dementia** (Förstl, 2009a; Mahlberg & Gutzmann, 2009a). In the following, these are shown in a generalised manner for the entity of dementia, instead of being assigned to specific forms of dementia (Mahlberg & Gutzmann, 2009a) as is customary in medicine. According to integral understanding, the dementia forms are to be understood as types, not as lines of dementia, as will be explained further below. In empirical research, the following factors are found in the context of dementia in the external-individual quadrant (without claiming to be exhaustive):

- Molecular and cellular level: β-amyloid plaques, hyperphosphilated tau protein, Lewy bodies, prions
- Organic causes: Normal-pressure hydrocephalus, microangiopathies, tumours
- External factors: Alcohol abuse, poisoning, cranial injury, vitamin deficiency (Mahlberg & Gutzmann, 2009a)

These lines are influenced in their development by various conditions, such as drug therapies (Benkert, Hautzinger & Graf-Morgenstern, 2007) or time of day (e.g. sun-downing phenomenon, Mahlberg & Kunz, 2009). Furthermore, the expression of these factors depends on typologies such as sex types (Neumann, 2009), dementia forms (Mahlberg & Gutzmann, 2009a) or genetic dispositions (Jessen, 2009b). Some of these aspects will be discussed in more detail in chapter 5.2.2.

The **line of behavioural patterns of dementia** can be differentiated with regard to the empirical data situation in this area using, among other things, the nursing-scientific theory of activities of daily living (ADLs) by Juchli (Köther & Gnamm, 1995). As an example, some data in this area are shown below for the ADLs "resting and sleeping", "moving" and "communicating" (Köther & Gnamm, 1995).

The external-individual dimension of dementia becomes apparent in the area of resting and sleeping especially in the research around sleep disorders (Mahlberg, 2009) and circadian rhythm disorders of people with dementia (Mahlberg & Kunz, 2009).

The activity area of moving shows data from various sources, from cycling tours with dementia patients (Schabacher, 2011) to the scientifically evaluated combination of memory training and psychomotor training of the SimA programme (Oswald, 2004). In this topic, the cross-connection to another aspect of the external-individual dimension of dementia, which is not considered further here, is obvious: Movement is one of the factors that, according to numerous studies, has been shown to be a preventive factor for dementia (Müller, 2008).

The activity area of communicating here refers to the ability of people with dementia to communicate. Numerous studies are dedicated to the area of non-verbal communication of people with dementia (Sachweh, 2009), furthermore, dementia also manifests itself on the external-individual level in particular in speech disorders such as aphasia and apraxia

[source]. Due to the conditional nature of communication in advanced stages of dementia, an integral dementia concept should also take into account the communicative behaviour of relatives (Engel, 2006) or carers or companions in general (Powell 2009).

The **line of abilities** includes not only the aspects of sensory abilities such as hearing impairments (Jonas, 2008), but also a positive concept of abilities, as is evident, for example, in the offer of dancing afternoons for people with dementia in a dance school (Arp, 2011).

The results of people affected by dementia in dementia screenings (e.g. Mini-Mental-Status-Examination, MMSE, Engel, Mück & Lang, 2009) can also be seen as an expression of the line of abilities according to integral understanding. The ability to draw a geometric figure (Engel, Mück & Lang, 2009) is, from a medical-psychological point of view, a statement about the expression of the 'disease' or the 'disorder' of dementia, but according to integral understanding it is 'only' the expression of a certain ability of an individual person. The interpretation as a dementia diagnosis only comes about through the evaluation criteria set by the developers of the respective screening; without the underlying catalogue of criteria (an influencing factor of the external-collective dimension of dementia), the ability cannot be interpreted as an expression of dementia, even from the perspective of empirical science.

5.2.2 Levels, states and types

The level model of the severity of dementia has already been described in its influence on the interior-individual factors of dementia (cf. ch. 5.1.2). In the exterior-individual quadrant, an increasing degree of severity in a person with dementia is shown, among other things, in objectively ascertainable changes in the activities of daily living (Förstl, 2009b).

The abilities of people with dementia in dementia screenings (cf. ch. 5.2.1) can also be interpreted as level models. Certain abilities that are tested in a screening (e.g. certain linguistic performances, cf. Engel, Mück & Lang, 2009) characterise the areas in the individual in which dementia-related development takes place. These are represented by the test results as levels, i.e. models of development over time. Here, the challenge indicated in Chapter 4 of representing downward regressive development with the structures of a model oriented towards forward upward development appears.

The medicinal-pharmacological therapeutic options can be seen as one aspect of the states of dementia in the external-individual realm. For medical science one of the focal points of research, medicinal therapeutics show themselves from an integral point of view as state areas in which the entity of dementia shows itself differently. Drugs are not a line of the exterior-individual quadrant (they are not part of the individual), nor are they levels of dementia in the exterior-individual domain, because they are not part of the development of dementia over time, but have an external effect on this development. In their influence on dementia, they are therefore to be understood as "temporary occurrences of aspects of reality" (Esbjörn-Hargens, 2009, 12, cf. ch. 3.1.5), because they change certain molecular

or neuronal patterns of the organism, but do not become part of it (cf. also ch. 5.2.3.1). Thus, the drug therapy of dementia, which takes up a large part of the attention in science and research, becomes one factor among many others in the view of the external-individual quadrant of the Integral Theory. However, it is an artefact of (collective) medical-scientific dementia research, and therefore has its own status in the external-collective quadrant (cf. ch. 5.4.1).

The types of dementia are one of the basic typologies of the entity dementia in the exterior-individual domain. They are a scientifically recognised differentiation model (Mahlberg & Gutzmann, 2009a) of the characteristics of the behaviour and organic changes of a person affected by dementia. Following Habecker (2010), the dementia types are to be understood as an expression of the variance of dementia processes on a horizontal level, i.e. they describe the numerous typical developmental paths of a dementia process, which always proceeds similarly, but with typical variations with regard to the lines, levels and states of this area. Types in this area that may need to be considered separately are the reversible dementias (Schulz, 2009). Other relevant typologies for the external-individual dimension of dementia may be gender types (Schmidt, Assem-Hilger, Benke et al., 2008) or genetic dispositions (Jessen, 2009b).

5.2.3 Internal and external view of dementia in the exterior-individual dimension

Also for the zones of the external-individual quadrant, the mentioned methodologies or scientific areas are only to be understood as examples, following the Integral Theory (Wilber 2006a). Figure 19 below gives an overview of possible questions of the internal and external view of the external-individual dimension of dementia (cf. ch. 3.2.2.3).

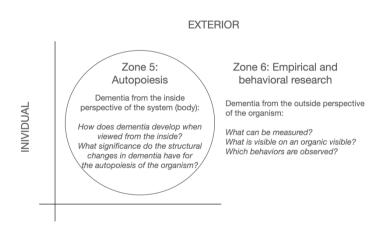


Fig. 19: Possible questions of the zones in the exterior-individual quadrant

Since the **theory of autopoiesis (zone 5)** as a model for the internal view of the external changes of the individual (cf. ch. 3.2.2.3) has not yet been applied to dementia, only an orienting presentation of a possible relevance of this theory can be shown here without presenting the theory in detail. Maturana and Varela (1987) describe the nervous system

as an operationally closed system that constantly 'produces' the world it perceives itself in such a way that it can only perceive those things for the perception of which it has also developed the structures. Changes in the environment of the human being (who, in contrast to the cell, is regarded as a so-called 'metacellular organism', Maturana & Varela, 1987) are regarded as perturbations (disturbances) that exist independently of the individual as part of the milieu in an operationally different system. Now, the living system (the individual) is not simply at the mercy of these factors, but determines whether and how it reacts to these perturbations, "it is rather the structure of the living being that determines what change occurs in it as a result of the perturbation." (Maturana & Varela, 1987, 106). The environment and the living being (as long as there are no destructive interactions) act as mutual sources of perturbation and trigger structural changes that serve the other system to maintain self-organisation, which is called structural coupling (Maturana & Varela, 1987).

A possible relevance of this theory for dementia arises from the following assumptions: Structural change of the whole organism occurs through the nervous system at the synaptic level (Maturana & Varela, 1987, 183), and these structural changes are fundamentally subject to the autopoiesis of the whole living being (ibid.). However, when the organism can no longer select the structural changes that enable it to continue to operate, it dissolves (Maturana & Varela, 1987, 187). Mechanisms such as apoptosis of nerve cells (Hessenauer, n.d.) can possibly be understood as mechanisms of dissolution within the framework of this theory, if the cell were no longer able to react to the perturbations of the environment with structural changes. The neuronal networks regressing through dissolution of individual cells would subsequently lead to a change in the experience of "the world out there", which in turn would affect the future perception of the world.

The **empirical sciences (Zone 6)**, on the other hand, as representatives of the external view of the external-individual dimension of dementia (cf. ch. 3.2.2.3), observe and measure the objectively perceptible facts in the individual (in contrast, for example, to epidemiology, which looks at the manifestation of dementia in a population, which is an aspect of the external-collective dimension). What is considered as dementia is the result of observations of certain behaviour of a certain individual, some organic findings in combination with criteria defined by certain institutions (external-collective dimension). The empirical sciences, including medicine and behaviouristic psychology, focus on the objective measurement of these externally perceptible factors. All the data of the lines mentioned in section 5.2.1 originate from this field of knowledge, so that a further elaboration can be dispensed with at this point.

In summary, this quadrant shows the contrast between a so far unusual, partly unknown view of dementia in zone 5 and the known methods and data on dementia in zone 6, which are generally accepted in the scientific community.

5.3 Interior collective dimension of dementia

From the individual quadrants, the focus now turns to the collective aspects of dementia, the 'we' being at the centre here. The interest in knowledge is directed towards the inner processes of a collective, a community or society that is involved in dementia in some way. The data of this quadrant are obtained from the observation and interpretation of the norms, values, rules and intersubjective behaviour patterns of the respective community. The sciences involved are, in the broadest sense, cultural and social sciences (cf. ch. 5.3.3), which ask, for example, how dementia manifests itself on the interior-collective level, or which cultural forms of coping different societies develop. The perspective changes from an individually objective one in the exterior-individual quadrant to an intersubjective perspective of dementia, to an understanding description of the 'felt we' of dementia in zone 3 (ch. 5.3.3.1) or the systematisation, a description from the outside of precisely this felt 'we' in categories of the participating sciences in zone 4 (ch. 5.3.3.2). The validity claim of this quadrant is justice.

5.3.1 Lines

Relevant lines are also named for this area in Integral Theory: Worldviews, intersubjective dynamics, linguistic meaning, cultural values, background cultural contexts, philosophical positions and religious understandings (Esbjörn-Hargens, 2009, 12). Transferring these specifications to the entity of dementia, different lines can be identified as areas of the development of intersubjective dementia, as shown in Figure 20.

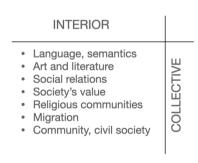


Fig. 20: Some lines of the inner-collective dimension of dementia.

As examples, some areas will be outlined here on the basis of selected data, where the entity of dementia as a 'felt we' (cf. ch. 3.2.2.1) comes to light.

The line of language asks, among other things, about the semantic meaning of the term dementia. The emergence of dementia via the concept of senility and in conjunction with the concept of Alzheimer's disease is shown by Kreutzner (2008). Following a government initiative in Japan, a new formulation for dementia-related changes was found to replace the previous term with meanings of 'stupid' and 'mindless' with a term meaning "challenge to cognition" (Whitehouse & George, 2009, 65). Whitehouse & George's (2009) 'debunking'

of the myth of Alzheimer's disease also falls within the linguistic lineage of the entity of dementia. The culturally defined terms for people who are 'afflicted' with dementia according to medical definitions are another expression of this lineage, as exemplified by the term "people with dementia" (Wißmann & Gronemeyer, 2008, 71).

Similarly, dementia is evident in the lineage of literature, where it is not the artifact of the printed work that is at issue (that would be an aspect of the external-collective quadrant), but rather the meaning content that the reader is able to access for him or herself, thus placing cognition in the realm of hermeneutic methodologies. A well-known example from the field of fiction is Suter's (1999) novel Small World; furthermore, two biographical publications by sons about their fathers affected by dementia (Geiger, 2011; Jens, 2009), among others, have recently attracted attention and increased public reception of dementia via literature. An overview of children's and young adult literature on dementia is provided by Jonas (2006). Also relevant in terms of conveying cultural meaning of dementia may be popular science publications on dementia, such as Jürgs' (2001) publication on Alzheimer's disease subtitled Spurensuche im Niemandsland [Searching for traces in no man's land], or Taylor's (2008) autobiographical exploration of dementia.

The lineage of social relations continues to provide numerous data on the 'felt we' of dementia. These can include, among others, the intersubjective aspects of care and support concepts that provide recommendations for shaping relationships with people with dementia (Engel, 2006; Feil, 1992; for other concepts, see Myllymäki-Neuhoff, 2009). Furthermore, data can be found on the intersubjective aspects of multiple relationships, such as relatives in general (Engel, 2007), spouses (Franke, 2005), or between grandchildren and their grandparents under the influence of dementia (Philipp-Metzen, 2008).

Another aspect that is still relatively unconsidered in research is the line of intersubjective relationships between people with dementia, where both situations of institutional living independent of care relationships would have to be taken into account, and also the relationships in self-help groups such as the Scottish Dementia Working Group (n.d.), whose organization is structured completely autonomously, i.e. without the influence of 'healthy' persons.

This list, as with the preceding dimensions of dementia, by no means reflects the state of knowledge from science, practice and civic engagement of dementia. It is therefore to be understood here only as exemplary for the range of representation of the entity dementia in the interior-collective quadrant.

5.3.2 Levels, states and types

By way of example, some of the lines of the previous section will be used to show how, from the point of view of an integral dementia concept, the findings in the various lines, i.e. areas of development of dementia, are also presented across various levels, i.e. stages of development. Likewise, some relevant states and types will be pointed out.

In the field of language, the use of the term "people with dementia" in the German literature (Wißmann & Gronemeyer, 2009), and in the English-language literature "people with dementia" (Ballenger, 2006), which increasingly replaces the use of terms such as "dementia patients" (Lind, 2000) or "demented" (Grond, 1997), can be understood as an expression of developmental levels. The meaning of the term further differentiates into different types of cultures and ethnic languages. Within these types, in turn, development takes place over time in the sense that the semantic meaning, the cultural interpretation of the "sign" of dementia has changed over time (cf. the situation in Japan; Whitehouse & George, 2009). Thus, we can speak of the individual languages as level models of dementia in the internal-collective quadrant, differentiated by type.

Some typologies of dementia have already become evident in the line of social relationships, for example, relationship dynamics differ, among other things, on the basis of relationship partners (types), for example, grandchildren or spouses as part of the relationship dyad (Franke, 2005; Philipp-Metzen, 2008). Possible states - a hypothesis to be tested for later research - could be, among others, wars or humanitarian disasters, which could potentially affect the integration of people with dementia in society.

5.3.3 Internal and external view of dementia in the internal-collective dimension

In the interior-collective dimension of dementia, too, a distinction is made between an interior and an exterior view of dementia (cf. ch. 3.2.2.1). Figure 21 gives an orienting overview of possible questions of the two zones regarding a recording of the intersubjectivity of dementia.

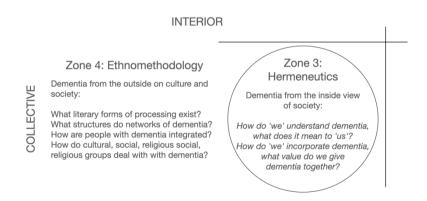


Fig. 21: Possible questions of the zones in the interior-collective quadrant.

For a hermeneutics (zone 3) of the intersubjectivity of dementia it seems to be necessary to develop different constructs of hermeneutic understanding for the different 'cultures' of communities of dementia. If one follows Schnell's (2008) thoughts, dementia also needs to be considered as part of a distinct (dementia) society, since "dementia does not only mean deficiency, degradation, or loss of mind, it can also manifest itself in an otherness that extends to a different normality (Georges Cangilhem)." (Schnell, 2008, 80).

Accordingly, a distinction must be made between, for example, intersubjectivity between persons not affected by dementia, in which dementia is a constituent or accompanying feature of the relationship, intersubjectivity between those affected and those not affected, as in everyday life in nursing homes, and intersubjectivity between those affected, taking into account both interactions between people with severe dementia in a nursing facility, but also interactions of people with dementia in a self-organized support group such as the Scottish Dementia Working Group (n.d.).

Ethnomethodology (Zone 4) is mentioned here as representative of the methodologies of an external view of the interior-collective dimension of dementia. Integral Theory gives few examples here that lend themselves to obvious application to dementia (Wilber, 2006a), ethnomethodology certainly offers starting points due to the relevance of the topic of dementia and migration. Orientation can further be found in Wilber's (2006a) characterization of ethnomethodology, which is "which deals wit the underlying codes, conventions, and rules of social interactions" (Wilber, 2006a, 154), which allows the cultural and social science data shown in Chapter 5.3.1 to be assigned to this zone.

In summary, these two zones reveal the patterns and relationships of respective social relations and meanings both from within the 'we', the 'felt we', and also from the external view of the 'we', the 'observed we'.

5.4 Exterior-collective dimension of dementia

For this final section of an integral dementia concept, the external-collective domain of dementia, objective, measurable data are collected on structures and artifacts of the system in which dementia is manifested. Participating scientific fields include economics, epidemiological health sciences, policy, and law. Also, findings from architecture or practice-based findings from interior design and garden design may be relevant to the representation of the entity of dementia in the external-collective quadrant. Further, this is the space of prevalence and incidence, of figures about the collective manifestation of dementia. The 'hardware' of medical-pharmacological sciences, which is developed for dementia diagnostics and therapy, further counts to this dimension.

An epistemic question in this field is how and where dementia is represented in the external-collective domain. According to the validity claim of this domain, the functional fit, it is asked where dementia has an impact and which structural adjustments are necessary to enable a dementia fit.

5.4.1. Lines

Also in this quadrant, dementia-related development takes place along many lines. For the exterior-collective domain, the integral literature points to geopolitical structures, eco systems, insurance systems, written legal codes, and architectural styles as characteristic lines of this dimension (Wilber 2001a, Esbjörn-Hargens 2009). From the scope of this quadrant,

the functional fit, one can formulate as guiding questions: Where does dementia show up in systemic aspects? Where does dementia prove to be a functional, structural fit, where not? What is being done to achieve this fit?

The lines mentioned are also relevant in the field of dementia, but are to be further differentiated and supplemented, so that in this work the lines shown in Figure 22 are considered relevant for the external-collective dimension of an integral dementia concept.

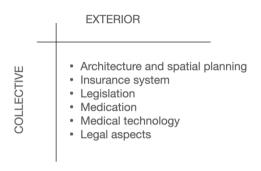


Fig. 22: Exemplary lines of dementia in the external-collective quadrant

The insurance system is a separate line of the system, in which dementia appears, as it has to develop necessary structures for a functional fit of all parts of the system (so also the people with dementia). In this context, dementia-relevant development is taking place in the areas of health insurance (SGB V, BMJ, 2011a) and long-term care insurance (SGB XI, BMJ, 2011b), among others. The different areas such as care benefits in kind (§ 36 SGB XI) and care allowance (§ 37 SGB XI) in home care for people with dementia are part of the system whose task is to provide structures to ensure dementia as a functional part of the system.

The **line of legal aspects of dementia** is dedicated, among other things, to the question of the general legal capacity of people with dementia (Schmoeckel, 2010) or the testamentary capacity of people with dementia in notarial matters (Lichtenwimmer, 2010). However, it must be noted that these are not 'capacities' in the sense of the upper right quadrant, but rather what is granted as capacities to people with dementia from a systemic perspective (lawyers being understood here as representatives of systemic structures).

Another line of the exterior-collective dimension of dementia is **architecture**, here related beyond the 'classical' retirement home to all (institutional) living concepts in which people with dementia are cared for. Approaches of architecture (Marquardt, 2006) and aspects of interior design such as the effect of lighting on people with dementia (Sust, 2009) are expressions of the system to 'fit' people with dementia into it. In the particular design of gardens (Rath, 2004) or in the simplest structural aspects such as the position of seating in recreation rooms of nursing homes (Strunk-Richter & Krämer, 2008), the influence of systemic structures on the entity of dementia becomes obvious in its interconnectedness with the other dimensions.

Finally, the structural data of dementia should be mentioned, as **lines of epidemiological development** (Ziegler & Doblhammer, 2009), in the field of **cost development in the health care system** (Kiencke, Rychlik, Grimm & Daniel, 2010) and the **general socioeconomic relevance of dementia** (Michel & Niemann, 2002). It is true for all factors that they represent areas of systemic development in whose structures dementia emerges. The area of **medicinal therapeutics** (Benkert, Hautzinger & Graf-Morgenstern, 2007) has already been discussed in the external-individual area in its influence as a temporary condition on the organism. This domain represents artifacts of the medical-technical system, as do the various imaging techniques (Holthoff, 2009); both aspects are independent developmental domains of the exterior-collective dimension of dementia.

Furthermore, guidelines (ICD-10, DIMDI, 2010; S3-Leitlinie Demenzen, DGPPN & DGN, 2009) and institutions (e.g., Demenz Support Stuttgart, 2010a.; Aktion Demenz, n.d. a) related to the entity dementia can be seen as expressing lines of dementia in the exterior-collective quadrant (as opposed to the meanings and value patterns they convey, which are line of the interior-collective quadrant).

5.4.2 Levels, states and types

As a level model of the exterior-collective quadrant, the development of the ICD criteria of the WHO can be considered. Comparing the development of the criteria over time, a change in the framework of the dementia entity can also be seen in these structures, including in discussions of the International Advisory Group on the ICD-11 catalog under preparation, which criticize the unsuitability of the mental illness criteria for nursing and health care (WHO, 2007, 3). The Advisory Group recommends a telescopic structure of the future criteria for nursing and health care as the lowest level, followed by further differentiated criteria for clinical use, on which further differentiated criteria for use in the research sector should be based (WHO, 2007). This would result in differentiated levels already in the definition of dementia, which could ensure improved applicability of the criteria in the respective sector.

Other level models can be found in the education and training sector of the nursing professions, recognizable among others by the "Levels of Knowledge and Skills" (Scottish Government, 2011), but also in the German training system for geriatric care with different qualification levels such as care assistants (GKV, 2008), certified geriatric care assistants (Land Hessen, 2007) and certified geriatric nurses (BMJ, 2009).

Nursing home architecture includes several areas where change can be understood as an expression of development over time, which could be based on changing requirements regarding a functional fit of aging and dementia in particular: In the area of home architecture, development can be described, among other things, in terms of the so-called four generations of retirement homes (Marquardt, 2006). These have continuously evolved with systemic change and the ever-present 'pressure to adapt' from the system and

dementia, so that the architecture of a nursing home can also be seen to adapt to changes in the system (cf. Marquardt, 2006).

Conceivable typologies of this quadrant include political systems, possibly also climatic zones (which affect models of nursing home architecture, among others), settlement areas (rural or urban structures, which can also affect nursing home architecture, but also economic aspects of dementia). However, since no evidence can be provided for these factors, typological influences must remain in the hypothetical realm for now.

5.4.3 Internal and external view of dementia in the exterior-collective dimension

Likewise, for the methodologies and theoretical concepts that are mentioned as representative for the inside and outside view of the exterior-collective dimension (cf. ch. 3.2.2.4) of dementia, the limiting remarks of the previous chapters apply to these aspects. In the following, the theory of social autopoiesis will be mentioned as an example for zone 7, the internal view of the exterior-collective dimension of dementia. The term 'systems theory' as representative of zone 8, the external view on the systemic aspects of dementia, is likewise only to be understood as a generic term for a larger number of scientific directions. Figure 23 gives a first impression of the zones of this quadrant and the guiding questions.

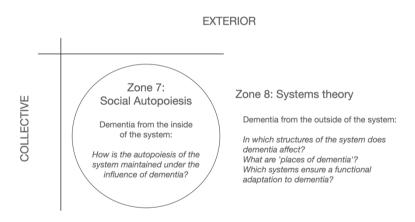


Fig. 23: Possible questions of the zones in the exterior-collective quadrant

Luhmann's theory of **social autopoiesis (zone 7)** (Kneer & Nassehi, 1993, ch. 3.2.2.4) has not yet been applied to dementia, nor has the theory of Maturana and Varela (1987), on whose approach Luhmann builds. It will be explained here only roughly orienting in a possible relevance for dementia. The theory of social autopoiesis distinguishes between the autopoiesis of, among others, neuronal, mental and social systems (Kneer & Nassehi, 1993, 58), each of which operates separately, i.e. reproduces itself. According to this understanding, human beings are not a single system, but consist of a multitude of closed self-referential systems (Kneer & Nassehi, 1993, 66). The mental as well as the social system are connected to their respective environment by structural coupling, and exchange takes

place by means of communication "as last units that cannot be further resolved" (Kneer & Nassehi, 1993, 65).

Assuming that social systems are self-referential systems that reproduce from themselves by means of communication (on Luhmann's concept of communication, cf. Kneer & Nassehi 1993), dementia can possibly be seen as a result of an altered autopoiesis of a consciousness involved in a communication: "A thought appears, but in the very next moment it submerges and is replaced by a new thought. Consciousness thus has to deal with a permanent decay of its elements." (Kneer & Nassehi 1993, 60). Dementia then appears in a basal form in that in this permanent decay of consciousness, individual elements can no longer be reproduced because another structurally coupled system, the neural system, can no longer reproduce certain neural patterns. (Here, however, it must remain open which changes in the structural coupling of the neuronal system may have led to the fact that these patterns are no longer reproduced). Consciousness must now adapt its self-preservation to these changed environmental conditions, which will cause it to change its own structure.

However, since social systems depend on certain environmental conditions for their self-preservation (Kneer & Nassehi, 1993, 69), a altered consciousness directly affects the system as one of these environmental conditions: "Thus, all communication would immediately come to a standstill if at least two consciousness systems were not involved in it." (Kneer & Nassehi, 1993, 69). If a consciousness changes, it thereby provokes or irritates communication as an independent, emergent level of order (Kneer & Nassehi, 1993) of the social system, which then in turn must adapt accordingly in its self-preservation.

The field of **systems theory (zone 8)**, on the other hand, can already draw on multiple data on a relevance of dementia in the system from the external perspective (cf. ch. 3.2.2.4). The results on some lines of the external-collective dimension of dementia mentioned in chapter 5.4.1 can be subsumed under an integral understanding of systems theory that "describes the patterns and interrelations of interactions between external objects (...) from an objective point of view." (Wittrock, 2008, 61). Various aspects of the exterior-collective dimension of dementia mentioned in chapter 5.4.1 and 5.4.2 take on the objective description of the systemic structures that ensure functionality of dementia.

To summarize, here, once again, after chapter 5.2.3, the phenomenon of a heretofore unapplied methodological or theoretical perspective on dementia in zone 7, as opposed to the scientifically well-founded area of zone 8, systems theory with its wide-ranging special references, becomes apparent.

5.5 Summary: Core structures of an integral dementia concept

In the preceding sections, a number of scientific findings about the entity of dementia have been transferred into the structural elements of Integral Theory by way of example. This

made it possible to model some structures of an integral dementia concept, focusing on the quadrants and lines of dementia, which are shown together in Figure 24.

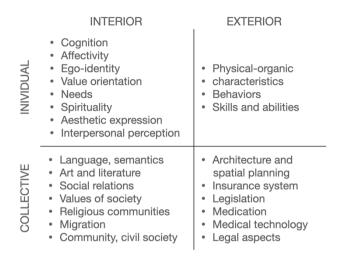


Fig. 24: Dimensions and lines of an integral dementia concept

Figure 24 clearly shows the four different dimensions of dementia, which originate from the scientific fields and epistemological traditions of the respective quadrants (cf. 3.2.1) and are subject to the validity claim of the respective quadrant (cf. ch. 3.2.1).

The findings about the interior-individual dimension of dementia (cf. ch. 5.1) are subject to the validity claim of truthfulness and give an insight into the interior experience or the subjective perception of what dementia is. The exterior-individual domain, with the scientific domains assigned to it, is subject to the validity claim of truthfulness; the findings of this dimension (cf. ch. 5.2) provide an insight into the various domains of dementia as they can be objectively perceived and described. For the findings of the interior-collective dimension, the claim of justice applies; they show how dementia is perceived, interpreted and integrated in communities (cf. ch. 5.3). Finally, the external-collective dimension of dementia shows how dementia is organized and structured under the validity claim of functional fit (cf. ch. 5.4) in order to maintain its fit in the system.

If we transfer the research data obtained in the preceding sections on the lines of dementia of each quadrant into a quadrant model, a relatively differentiated picture of an integral dementia concept emerges, as figure 25 shows.

| | INTERIOR | EXTERIOR |
|------------|---|--|
| INIVIDUAL | Insight into illness Emotional situation of relatives Self-image of those affected Kitwoods needs model Spiritual needs Aesthetic expression | Molecular aspects Organic causes External triggers Exercise Rest and sleep Communicative abilities Sensory limitations Behavior in tests and screenings |
| COLLECTIVE | Meaning of "dementia" Biographies Fiction Marriage and grandparenthood Self-help groups Care concepts Civil society engagement | Home architecture Care insurance Business and testamentary capacity S3 Guideline Dementia ICD-10/ ICD-11 Levels of Knowledge and Skills Epidemiology Cost of illness |

Fig. 25: Overview of detailed aspects of the draft of an integral dementia concept

Figure 25 thus shows a detailed subdivision of the entity dementia on the basis of the structural model of the lines, as it has appeared in the literature according to the specifications for the research process mentioned in chapter 4.4. As justified there, this work put the emphasis on the structural models of the quadrants and the lines, while the other aspects were thematized in an overview way.

In summary, according to Figure 25, the aspects of the interior-individual dimension of dementia (cf. ch. 5.1, for all data mentioned in the following section, see references in the respective chapters) are the insight into the disease of both affected persons and, for example, in a modified form of general practitioners, furthermore the emotional situation of relatives, the self-image of affected persons, Kitwood's model of needs, spiritual needs of various persons involved, or the aesthetic self-expression of persons with dementia.

Aspects of the exterior-individual dimension (cf. ch. 5.2) were molecular aspects, different causes of dementia, movement, resting, sleeping and communication as examples of activities of daily living, sensory limitations and the behavior of affected persons in tests and screenings. Here, in contrast to the interior-individual dimension, the focus was exclusively on the perspective of people with dementia, not also other people involved in dementia.

In the interior-collective dimension of the entity dementia (cf. ch. 5.3) data on the (culturally dependent) meaning of the term dementia are available, furthermore biographies of people with dementia, as well as fictional interpretations of the topic. Marriage and grand-parenthood under the influence of dementia are assigned to this area according to integral criteria, as are self-help groups, care concepts, or civic engagement.

Aspects of the exterior-collective field of dementia (cf. ch. 5.4) were found in particular in the topics of home architecture and long-term care insurance, but also in the (structural) questions of business and testamentary capacity of people with dementia, in various

guidelines such as the S3 guideline on dementia, further development in the field of ICD-10/ ICD-11 or in training structures such as the Scottish Levels of Knowledge and Skills. Finally, findings from epidemiology and on costs of disease complemented this field.

Thus, a detailed picture of a blueprint for an integral dementia concept emerges based on two structural elements of Integral Theory, the quadrants or dimensions and the lines of development. Dementia occurs respectively dementia 'is' (in the sense of a unspecified existence, cf. ch. 4.2) in all these areas of individual as well as collective, inner as well as outer development.

Individual examples for an application of levels, states and types in their relevance for the entity dementia completed the explanations in this chapter. Since they were only exemplary and not detailed, a graphical inclusion is omitted here. An overview of the relevance of the methodologies of the different zones for an integral dementia concept was also presented. Also these are not shown here again, it is referred to the figures 17, 19, 21 and 23.

The main thesis of this paper, that Integral Theory is suitable for the elaboration of a blueprint for an integral dementia concept that can link and integrate wide-ranging findings on the entity of dementia within the conceptual framework, can be considered confirmed according to the data presented here. A blueprint for an integral dementia concept has been presented in this thesis.

The necessary reduction to two structural elements due to the methodological requirements (cf. ch. 4) will be discussed in chapter 7 in terms of its effects on the design and the implications for further research work.

The following chapter 6 is dedicated to the empirical examination of the scope of the presented draft for an integral dementia concept based on a literature analysis.

6 Empirical evaluation of the integral dementia concept

[In chapter 6 there are methodological shortcomings in the sense of circular reasoning, which the reviewers of my work did not criticize, but which I myself consider to be inaccurate scientific work, which I would like to point out. The imprecision in this chapter was due to the framework conditions, which is an explanation but not an excuse.]

Now that the main thesis of this work has been confirmed in the previous chapter, the related thesis that an integral dementia concept is comprehensive enough to incorporate a wide range of knowledge about dementia into its structure will be examined (cf. ch. 4.4.2).

In order to obtain a meaningful (but not representative) sample of aspects in the context of dementia, a random sample from the Medline database was chosen as the basis for the empirical review. All titles listed in Medline under the keyword dementia were selected;

publications in German from 2011 were chosen as a filter in order to be able to check current data. This resulted in a sample of 45 publications. One dataset was excluded from the content check due to a lack of reference to dementia, leaving 44 datasets. These were categorized according to the topics they focused on using the dimensions of dementia developed in chapter 5 (internal-individual, external-individual, internal-collective, external-collective) with a literature analysis.

6.1 Results of the literature analysis

After analyzing the data sets and evaluating the categories, 11 data sets or publications with a focus on one dimension of dementia (hereinafter referred to as 'one-dimensional'), 22 data sets with a focus on two dimensions ('two-dimensional') and 11 data sets with a focus on three dimensions ('three-dimensional') were identified. The detailed findings are presented and described graphically below.

Eleven publications are categorized 'one-dimensionally', i.e. they only focus on topics of a single dimension of dementia according to the integral dementia concept. Figure 26 provides an overview of the distribution of the one-dimensional publications in the quadrants. While no publication focuses exclusively on the internal-individual area, three publications focus on the external-individual area, and four each on the internal-collective and external-collective areas of dementia.

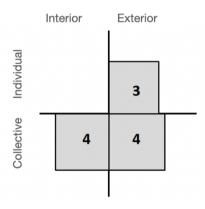


Fig. 26: One-dimensional publications in the quadrants

22 of the 44 publications focus on two dimensions of dementia, i.e. indicate a link between two aspects of dementia in the sense of an integral dementia concept. Publications that focus on both the external-individual and the external-collective areas of dementia predominate, with 13 publications compared to a total of nine publications in all other constellations, as Figure 27 shows. Four publications address aspects of the two internal dimensions of dementia, while two publications each focus on combined aspects of the two individual and the two collective dimensions. One publication combines topics of the external-individual and internal-collective areas of dementia (see Fig. 27).

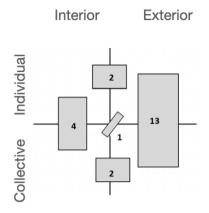


Fig. 27: Number of two-dimensional publications in the quadrants

A further eleven publications focus on aspects of three dimensions of dementia, with a relatively balanced distribution (Fig. 28). The informative value of this data is low due to the strong overlaps and the relatively balanced distribution, so this result is not discussed further. However, the data are included in a summarizing evaluation (Fig. 29), as are all the previous ones.

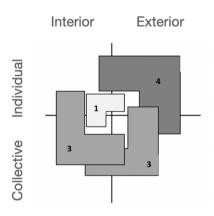


Fig. 28: Allocation of three-dimensional publications in the quadrants

6.2 Summary of the findings

Taking the entire sample together, aspects of the internal-individual dimension were focused on a total of 15 times, the external-individual dimension 26 times, aspects of the internal-collective dimension 19 times and aspects of the external-collective dimension 28 times. Figure 29 provides a graphical overview of the results.

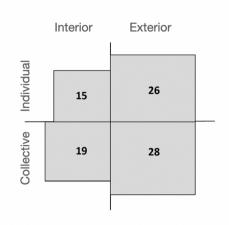


Fig. 29: Total number of aspects focused on in the publications in the four dimensions of dementia

This presentation clearly shows a predominance of the external dimension of dementia with 54 mentions compared to the internal dimension of dementia with 34 mentions. Furthermore, the collective aspects with 47 thematizations outweigh the internal aspects with 41 mentions. This shows the same tendency in the summary as in the individual results, i.e. a stronger weighting of the external and collective aspects in the analyzed publications. It is worth mentioning the number of thematizations of aspects of the internal-individual dimension of dementia, which do not occur as a single topic (see fig. 26) and are therefore only addressed in combination with other aspects of dementia.

Before these results are discussed in detail in the following section, figure 30 shows an overview of the main content of the publications.

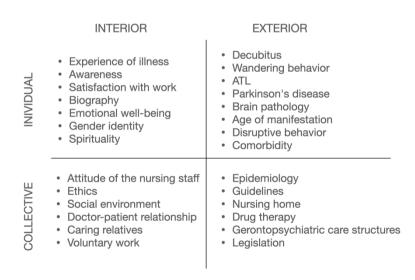


Fig. 30: Selected aspects of dementia from the sample

If these data are compared with the data in the summary of the integral dementia concept in figure 25, it becomes clear that the findings of the literature study in chapter 5 largely overlap with the results of the empirical review. The deviations, where they exist,

nevertheless show a great deal of similarity in terms of content. A detailed discussion of the findings is provided in the following section.

6.3 Evaluation

According to the present study, the first thesis of this work (see ch. 4.3) can also be considered confirmed from an empirical point of view: An integral dementia concept, outlined in its main features in chapter 5, provides the framework to assign all aspects of dementia, represented by a sample of dementia publications in chapter 6, to at least one place in the concept. All data sets in the sample can be assigned on the basis of the categories of an integral dementia concept, whereby differentiation and assignment according to uni- and multidimensional publications is also possible.

There is a dominance of the right-sided, external dimension compared to the internal dimension of dementia (54 vs. 34 publications, see fig. 29), but also a predominance of the collective aspects of dementia compared to the individual aspects of dementia (47 vs. 41 publications, see fig. 29).

The inner-individual area of dementia is the least represented in the publications of the sample used here, which is shown both by the total number of 15 publications focusing on this area (see fig. 29) and also by the absence of this area in the one-dimensional publications (see fig. 26). The internal-individual aspects do not appear to be the focus of independent consideration in this sample.

Although the absolute numbers are also only slightly higher compared to the internal-individual area (see fig. 30), the internal-collective area is slightly more represented with 19 publications and is found in all combination forms, without any particular conspicuous features. However, it is represented in less than half of all publications in the sample.

The external-individual area is the second most frequent topic area with 26 thematizations in the total of 44 publications in the sample, and is found in 50% of them in combination with the external-collective area alone (see fig. 27).

The external-collective area is the most frequently addressed topic in this sample with 28 thematizations. It is mainly discussed in connection with the external-individual area (see fig. 27).

From this, it can be concluded that the dementia discussion represented in this sample has a greater focus on the external dimension of the dementia entity. Questions about external-collective structures that make dementia "suitable" (in the sense of the underlying validity claim) for the surrounding system have the highest proportion in this sample. The physical aspects and the behavior of individuals in connection with dementia are slightly behind as an external-individual dimension.

However, the results of this sample, which are visualized in figures 26 to 29, also show that the second thesis regarding the evidence of a dominance of medicine (see ch. 4.3) cannot be confirmed on the basis of the purely numerical data. Although it can be concluded from the structures of the dementia concept developed in chapter 5 that the dominance of the external dimensions of dementia in the sample correlates with a dominance of medical findings, this cannot be deduced from the figures themselves.

However, if we look at the differentiated data situation based on the lines of dementia found in the sample, as shown in figure 30, the following becomes apparent: The exemplary data on, among other things, pressure sores, wandering behavior and Parkinson's disease (as original fields of activity of medicine, cf. ch. 5.2) in the external-individual dimension, on which the publications focused, are largely aspects of medical or gerontopsychiatric science. The aspects focused on in the sample, such as medication, guidelines and geriatric psychiatric care structures in the external-collective dimension of dementia, can largely be assigned to medicine and geriatric psychiatry (cf. ch. 5.4).

The detailed analysis thus provides strong indications of a correlation between the preponderance of data sets from these quadrants and a preponderance of medical findings in these quadrants. However, as no concrete distributions were collected here, no clear evidence can be provided for this thesis. In a further analysis, it would be necessary to work out the categories in a more differentiated way using the lines, levels, states and typologies of the integral dementia concept and to re-examine the sample. However, this is not done here, as the confirmation of the first thesis and strong evidence against a rejection of the second thesis are considered sufficient results.

7 Integral Theory as the Basis for an Integral Dementia Concept. Discussion

The aim of this thesis was to create a blueprint for an integral dementia concept based on the structural models (cf. ch. 3.1) and the concept of Integral Methodological Pluralism (cf. ch. 3.2.3) of Integral Theory. This outline could be derived in chapter 5 using data from dementia research and other areas of knowledge about dementia. Chapter 5.5 shows a graphical representation of the design based on the superordinate lines (fig. 24) and on the detailed data in the individual dimensions of dementia (fig. 25).

In chapter 6, the thesis that an integral dementia concept is suitable for integrating and linking data from a broad spectrum of knowledge about dementia was empirically tested. On the basis of a literature analysis of scientific publications on dementia, it was shown that all the data sets could be assigned to at least one dimension of dementia (cf. ch. 6.1), as shown in the draft of an integral dementia concept (cf. ch. 5). Furthermore, the data showed that the draft could be used to visualize the dominance of medical issues in the scientific discussion represented here (cf. ch. 6.3).

Thus, according to the findings presented here, Integral Theory provides the appropriate framework to represent the entity of dementia in its multidimensionality. An integral dementia concept thus eliminates the perspective viewpoint adopted by some dementia concepts. The draft presented here shows that a wide-ranging picture of dementia can emerge by bringing together different epistemological traditions and scientific fields (cf. ch. 5.5). This allows to see dementia from several perspectives at the same time and shows for all perspectives the fundamental same recognition as a relevant contribution to a holistic picture of dementia.

Furthermore, the design of an integral dementia concept offers the opportunity to present key findings in the current scientific discussion on dementia. In the current research literature reviewed here, a dominance of external aspects of dementia could be shown and visualized using the quadrant model (see figs. 26 - 29). In the detailed analysis of the aspects of dementia focused on by the research literature, a dominance of medical aspects was demonstrated (cf. ch. 6.3).

Various aspects of an integral dementia concept were only hinted at in this thesis in their potential for further integral dementia research. The structural elements of levels, states and typologies, which were only reviewed in overview due to the necessary methodological limitations (cf. ch. 4), and the different zones of Integral Methodological Pluralism (cf. ch. 3.2.2) showed points of contact for further insights into dementia from an integral perspective.

The challenge formulated in chapter 4, to describe a phenomenon of consciousness that includes regression on the basis of a theoretical theory oriented toward forward or upward development, was met by the outline for an integral dementia concept, but the specific topic was not captured in detail by the methodology used. It will be the task of further

research to investigate the interrelationships between different developmental directions, in particular through the increased use of level models.

In this context, understanding of medications as states in the exterior-individual realm should also be pointed out once again, which takes an unusual look at medicinal therapeutics and especially at the intensive research behind them: In this outline for an integral dementia concept, medications occupy a rather marginal place; they are understood as artifacts of the exterior-collective quadrant (cf. ch. 5.4.1) and as such induce alterations of states in specific lines of the exterior-individual quadrant (cf. ch. 5.2.2). This perspective on pharmacological therapeutics does not devalue pharmaceutical research and its 'artifacts', but it does relativize their status - at least from an integral point of view.

Here the potential of an integral dementia concept to be deepened with an extended methodology becomes apparent: it should go into depth on the many individual aspects of dementia as already shown in this draft, research further aspects, describe different levels in detail in the different lineages, question the influences of different conditions and consider in detail the influence of typologies on the aspects mentioned so far. It is also necessary to show connections between the different dimensions, lines and levels and to try to find them where no connections can be found so far.

A comprehensive integral dementia concept may be able to show how the lines and levels of the dimensions of dementia are interwoven and could serve as a frame of reference for practitioners as well as theorists with respect to their own standpoint in the fabric of the entity of dementia as well as with respect to other standpoints, insights, and techniques. The outline of an integral dementia concept presented here shows approaches to this.

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Draft for an integral concept on dementia

- Abstract -

<u>Background:</u> Scientific and public discussions show a wide range of different, and often conflicting, definitions of dementia. Medical characterizations are observed to presently dominate this debate, whereas more popular approaches are only emerging. As yet no integral combination of these two schools of thought is evident.

<u>Object:</u> A draft integral concept on dementia, based on Wilber's Integral Theory, is developed and tested for applicability.

<u>Approach:</u> The quadrant model and structural elements of the Integral Theory, along with implications of the Integral Methodological Pluralism form the theoretical basis for the transition of selected scientific data on dementia into an integral concept. The relevance and applicability of this draft concept has been tested against a sample of scientific publications on the subject of dementia.

<u>Results:</u> A draft integral concept on dementia based on the structural elements of quadrants and lines was developed. The hypothesis of this work assuming a principal applicability of the Integral Theory for a concept on dementia was confirmed. The literature review showed each of the sampled publications to meet at least one category of the integral concept on dementia. This also confirmed the necessary reach of the concept to cover a broad range of dementia aspects.

<u>Discussion:</u> Due to the deliberate limitation of the integral concept on dementia on two structural elements it is suggested to further differentiate and research the potential reach of the integral concept on dementia by also including the other structural elements and zones of Integral Methodological Pluralism.