

Chapter

1

Different Perspectives on Dementia

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1 A Brief History of the Concept of Dementia

1.1 Earliest Historical Traces of Dementia

The earliest references to dementia were discovered in an ancient Egyptian text written in the twenty-fourth century BCE. Even though it is not a medical record, the text describes clearly in hieroglyphs the situation of Ptah-Hotep, who was a vizier during the Fifth Dynasty of Egypt. According to the text, Ptah-Hotep spent every night becoming more ‘childish’. His inability to remember yesterday was also noted. Progressive behavioural changes as well as memory decline suggested that Ptah-Hotep was developing a dementia syndrome [1]. Ironically, he was highly esteemed for writing maxims, early Egyptian ‘wisdom’ literature, that instructed young men on appropriate behaviour and promoted self-control instead of childishness. The next identified reference to dementia or mental decline in old age was in the writings of classical authors.

1.2 Transition from Age-Related Senility to Dementia

Papavramidou [2] studied ancient Greek and Byzantine writings from the seventh century

BCE up to the fourteenth century CE in order to examine how people viewed ageing, senility or dementia in the classical era. She studied literary texts as well as scientific manuscripts and concluded that the history of dementia may be divided into two periods distinguishing between different types of ontologies associated with mental decline, the period before and after Posidonius in the late second to the early first century BCE (see Figure 1.1).

In the first period, authors mainly refer to dementia or senility as a condition brought forward by age. Indeed, already in the seventh century BCE, Pythagoras proposed that old age came with mental derangement. Specifically, a regression of mental faculties began at age 60 and by the age of 80 one would have reached a state of ‘imbecility’ or ‘infancy’. Two centuries later, Hippocrates referred to a similar phenomenon using the term ‘*morosis*’ (*becoming a child*) as a decline in the intelligence associated with ageing. Plato and Aristotle explained this decline as a result of bilious ‘humours’ or excessive black bile that was trapped in the body in old age and hence led to forgetfulness and reasoning problems.

However, in the second period, starting with Posidonius in the late second to the early first century BCE, there was a differentiation of the medical ontologies relating to dementia.

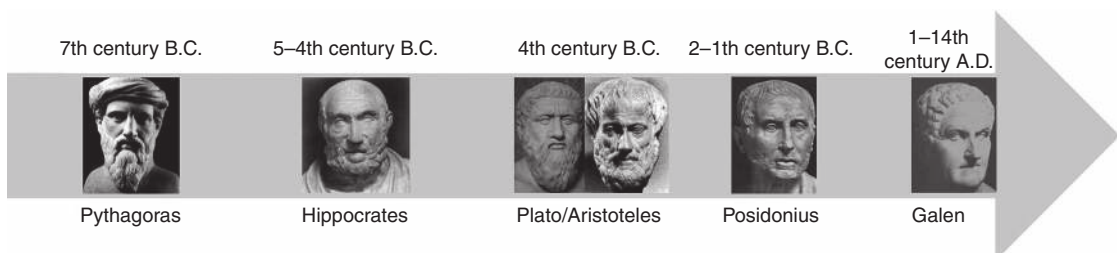


Figure 1.1 Scholars addressing senility and dementia in the Greco-Roman period

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Posidonius was the first to separate dementia due to old age ('leros') from dementia due to other causes ('morosis'). In a similar vein, Cicero – second century BCE – noticed that not all older people developed 'senile imbecility', only the 'weak'. According to him, an active mental life could offer the possibility of postponing senility. In the centuries that followed, many causes for dementia were described. Galen in the late first to the early second century CE clarified that a little humidity adding to cold in the brain was the main reason for morosis, as this mixture leads to inertia of the brain. Aretaeus in the second century CE referred to morosis occurring when melancholia aggravates. Psellus in the eleventh century and Actuarius in the thirteenth to fourteenth century CE wrote that cold and humidity specifically affect the ventricles of the brain, thus causing morosis. These concepts and ideas were maintained for several centuries as during the 'dark' Middle Ages, advances in understanding of dementia halted abruptly. Even though people were undeniably afflicted by dementia in this period, no relevant written sources are known.

According to Berchtold and Cotman [3], the next notable step in understanding dementia after the classical period was taken in the early 1600s during the Enlightenment. The English philosopher Francis Bacon wrote a book entitled *Methods of Preventing the Appearance of Senility* in which he noted that old age is the home of forgetfulness. In the second part of the seventeenth century, different types of dementia were characterized by Thomas Willis (1621–75), who was the personal doctor of Charles II. In his book *Practice of Physick*, he suggested that dementia might result from: (1) congenital factors, (2) age, (3) head injury, (4) disease or (5) prolonged epilepsy.

Only in the eighteenth century was 'senile' dementia considered distinct from usual ageing since the emerging new science of post-mortem study had shown that people with this condition had smaller brains than their healthy counterparts [4].

1.3 Biomedical Model with Alzheimer's Disease as the Public Face of Dementia

In the 1890s, Alois Alzheimer and Otto Binswanger extensively described the critical role of atherosclerosis in the development of brain atrophy and coincident senile dementia. A decade later,

Alzheimer was the first to discover specific changes in the brain that might be associated with symptoms of dementia. He studied a relatively young woman, Auguste Deter, who displayed progressive personality changes, confusion, suspiciousness towards her husband and hallucinations. Afterwards, pronounced memory problems occurred [5]. After her death at age 56, Alzheimer investigated changes in her brain post-mortem and found senile plaques that had been observed before only in older people, and first described neurofibrillary tangles. He reported on this in a case study entitled 'About a Peculiar Disease of the Cerebral Cortex' in 1907 and gave a lecture that received little attention.

For most of the twentieth century, Alzheimer's disease (AD) was considered a rare condition that affected mainly younger people and caused 'pre-senile' dementia. Hardening of the blood vessels, on the other hand, was considered a major contributor to cognitive decline in late life. Moreover, the causes for hardening of the blood vessels were sought in the organization of society that forced seniors to become inactive and isolated. According to Rothschild and many other psychiatrists, reduced stimulation of the brain was believed to result in cognitive deterioration [4].

A shift occurred in the early 1970s when studies of large numbers of post-mortem brains of older individuals observed extensive senile plaque loads that correlated with the clinical occurrence of dementia [6]. This shifted the field to attributing senile dementia to 'Alzheimer' pathology as opposed to vascular pathology and brought forward the term 'senile dementia of the Alzheimer's type', later to be replaced by AD irrespective of age, although early-onset (i.e. before the age of 65) and late-onset AD do have some different clinical features.

While recognition that senile plaques contain an amyloid protein was first proposed by Bielschowsky [7], the insoluble nature of the deposited protein made biochemical characterization difficult. With advances in molecular techniques in the 1980s, it was possible to sequence the amyloid protein and then clone the encoding gene, the amyloid precursor protein (APP) gene. The APP gene is located on chromosome 21, which aligned with the observation that trisomy 21 (Down's syndrome) individuals universally develop AD pathology by their early 40s with most also developing dementia. Subsequently,

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mutations in the APP gene were identified in autosomal dominant early-onset AD and soon after in presenilin genes that influence APP processing. This led to the formulation of the amyloid cascade hypothesis that postulated that the primary pathology is in amyloid deposition, which then leads to neurofibrillary tangles, synaptic dysfunction, neuronal loss and symptoms. Alzheimer's disease thereafter remained the 'face' of dementia for a long period. However, increasingly, it has become clear that there are many 'faces' of dementia and many degenerative illnesses that trigger cognitive decline or behavioural changes and subsequent dementia.

1.4 The Current Definition of Dementia

Dementia is a condition that may be caused by a wide range of diseases. Specifically, dementia is defined as a clinical syndrome of global cognitive decline affecting one or more cognitive domains, including complex attention, learning and memory, language, executive function, perceptual motor function and social cognition. The cognitive decline is severe enough to cause loss of independence by impairing the capacity to perform instrumental and/or basic activities of daily living. Individuals with dementia may experience difficulties that are so pronounced that they cannot live independently and over time become fully dependent on others.

Alzheimer's disease is the most common form of dementia, accounting for approximately 60% of all dementia diagnoses either alone or in combination [8]. However, many diseases are associated with dementia. The most recent (fifth) edition of the *Diagnostic and Statistical Manual (DSM-5)* replaces the term 'dementia' with 'major neurocognitive disorder' (NCD) and also distinguishes between acquired and developmental NCD, although many of the conceptual challenges are common to both [9].

1.5 The Spectrum of Cognitive Decline

In older people, dementia can be conceptualized as a syndrome encompassing advanced cognitive and functional decline, representing one end of a loose continuum ranging from 'usual' ageing to subjective cognitive impairment, mild cognitive impairment and finally dementia [10].

Usual – as opposed to 'normal' – cognitive ageing is characterized by reduced mental speed and less working memory capacity, leading to

difficulties in spontaneous recall, less ability to multitask, slower organization and the appearance of greater indecision. These changes typically do not interfere with the level of functioning in an individual and do not cause distress. Subjective cognitive decline (SCD), on the other hand, refers to an experience of cognitive failing that is distressing to the individual. Subjective cognitive decline is not a universal aspect of ageing, and it should be noted that many individuals with dementia do not perceive and are not distressed by their cognitive impairment. There are several possible causes of SCD. For some individuals, the experience of deteriorating cognitive skills might be a first signal of a pathological process that has not yet been detected in neuropsychological testing or brain imaging. For others, these distressing subjective changes may not reflect brain pathology, but rather result from a tendency to be introspective or to value cognitive functioning more than other domains of functioning. For yet others, this might reflect experiences resulting from depression, sleep impairments or alcohol use.

Mild cognitive impairment (MCI) is different from SCD because cognitive decline, beyond what might be expected from usual ageing, is present but does not impair functioning enough to be dementia. These alterations are detected in neuropsychological testing and others also notice a change in functioning [11]. Still, a person with an MCI can function at a high level and continue to live independently. Clinicians distinguish single-domain and multiple-domain MCI, as well as amnesic and non-amnesic MCI. These all have different prognoses, although with enough time most individuals with MCI develop different types of dementia, which is why MCI is often referred to as a dementia 'prodrome' [12, 13]. For instance, an amnesic, multiple-domain MCI may result in Alzheimer's dementia more often than a non-amnesic, single-domain MCI [14]. In contrast, non-amnesic MCI appears more likely to be a prodrome for non-Alzheimer's dementia.

Dementia, finally, represents the most severe form of decline, in which a person is no longer able to function independently, with the term 'de-mentia' referring to the loss of mind. As is common in this 'medical' discourse, the most important discriminator of dementia from MCI or usual ageing is in the functional and social domain, referring to the possibility to

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function day to day independently or need support from others.

While there have been considerable scientific advances in understanding the pathogenesis of the several dementia aetiologies, many challenges remain. First, the distinction between a disease, referring to the underlying pathology, and a syndrome, referring to the impact a disease has on the experience and functioning of an individual, often remains troublesome to clinicians as well as to patients and their families. As a result, people are unsure concerning the prognosis of a condition, or which types of symptoms can be understood as a part of the disease and which symptoms might represent a psychological reaction to disease symptoms. Another issue is the current focus on early detection of diseases, even in the presymptomatic phases. Often, to people in whom a vulnerability to develop a certain disease has been detected, such a vulnerability is implicitly considered a first stage in the disease process [15]. Even to clinicians or researchers, this distinction is not always clear. This may cause unnecessary distress, even more so as there is currently not yet a cure for the neurodegenerative causes underlying dementia.

To add to the confusion that sometimes arises from the different names that exist for a condition characterized by progressive cognitive decline, the latest version of the DSM-5 has utilized an alternative categorizing system to refer to cognitive impairment [9]. As mentioned earlier, the manual distinguishes between mild and major neurocognitive disorders corresponding with MCI and dementia, respectively. Indeed, dementia was considered as a stigmatizing label that needed to be replaced by a more neutral reference to the symptoms that are observed [16, 17]. However, there was no clear consensus on the use of the terms ‘major’ and ‘mild’ neurocognitive disorder [17, 18].

2 Broader Models of Dementia

2.1 Challenges to the Traditional Medical Model

The development of a biomedical model has certainly advanced the approach to dementia. In previous centuries, largely devoid of scientific medical knowledge, individuals with symptoms

of dementia such as disorientation or hallucinations were at risk of being persecuted for witchcraft; they were stigmatized and often isolated. Also, old age was often unconditionally associated with senility.

Fortunately, biomedical research has enlightened some of the pathogenic mechanisms behind dementia, hence making it an identifiable disease that does not warrant punishment or exorcism. Instead a treatment is required whereby the primary focus is on reversing impairments by means of ‘medical-somatic’ therapy or pharmacotherapy. Still, the application of a bygone biomedical model aimed at curing impairments caused by an illness has been limited as there is no cure for many of the neurodegenerative causes of dementia and quite often there are few effective pharmacological treatments of burdensome disease symptoms such as memory loss and disorientation [19]. Finally, neurobiological changes can explain only some of the considerable variety that is observed in individuals with dementia, with little conformity to any predetermined stage-like progression.

Hence, an excessively narrow application of the medical model risks minimizing the psychological and social sequelae of the disease, especially its effects on a person’s experience of and reaction to certain symptoms. It also carries the risk of limiting the therapeutic potential of interventions focussing on the social environment by underappreciating the role of caregiving in patient outcomes.

Fortunately, in the 1970s, treatments were also starting to focus on the consequences of dementia, concentrating on how to deal with impairment, the reorganization of the living environment and social environments. Also, psychosocial care gradually gained importance, defined as the treatment of psychological and behavioural symptoms that occur when an individual tries to cope with or adapt to the limitations caused by dementia (see Figure 1.2) [20–21]. This treatment aims to support the person with dementia and their family and thus increase well-being.

2.2 Biopsychosocial Models of Dementia

A treatment that encompasses all three perspectives and that considers interventions focussed on cure, rehabilitation and support as complementary is the biopsychosocial model, which was

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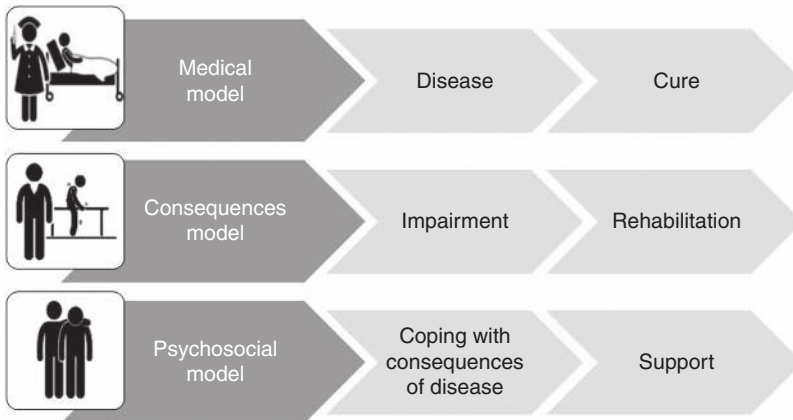


Figure 1.2 Different perspectives in the treatment of dementia [19]

introduced in 1977 by the internist and psychiatrist George Engel at Rochester University Medical Center in the USA [22]. He stated that to understand the full impact of an illness and treat it adequately, one should not just consider biological factors, but also personal and social factors of the individual with the illness.

In the 1980s and 1990s, many researchers developed biopsychosocial models that focus specifically on psychogeriatric care and dementia. A review by Finnema et al. [21] describes among others the dynamic systems analysis (DSA) model, utilizing a system-theory perspective in which complex interactions are emphasized instead of 'simple' and linear relationships. Hence, treatment of symptoms coinciding with dementia is based on the understanding of symptoms as the result of an interaction between somatic disease, cognition, personality, communication, the social environment and life history. Changes in any of these factors may have a therapeutic effect by altering the interaction.

Many practical applications exist of such biopsychosocial models. For instance, a major success in the USA is the person-centred, individualized Maximizing Independence at Home (MIND at Home) approach, which was developed in 2006 at Johns Hopkins University; it derives from an assessment of the individual needs of persons with dementia living at home, along with those of their caregivers [23–24]. It accounts for psychosocial determinants of health and behaviour and appreciates the importance of individual psychology in the development of illness and the central role of non-pharmacological therapies in improving clinical outcomes and quality of life. The assessment leads

to a tailored set of interventions to address these needs using continuously evolving, evidence-based protocols. The MIND approach has been shown to delay transition from home to a nursing home, improve life quality and reduce care burden and healthcare costs.

Similarly, in the UK, Spector and Orrell [25] have developed a biopsychosocial approach which can be used as a tool for understanding individual cases (see Figure 1.3).

In this illustration, a 75-year-old person with Alzheimer's dementia is admitted to hospital as a result of increased anxiety and the need to constantly be with the partner, who reports a great care burden. Psychologically, there are events in the past that cannot be changed. The man lost his mother at an early age. Additionally, his father was unable to be responsive and care for his son, as he was experiencing a complicated grief process himself. Biologically, AD causes disorientation and memory problems. Therefore the environment is often unfamiliar, which causes anxiety, and the man seeks reassurance through proximity of carers. At home, this is usually the partner. Finally, sensory deficits increase feelings of being isolated and alone. Interventions can be aimed at reducing this feeling of loneliness and hence decreasing levels of anxiety. Specifically, proximity to others may be promoted, and sensory function may be ameliorated. Feelings of anxiety may hence be reduced. In some cases, however, when other interventions appear insufficient, pharmacological treatment can be indispensable to alleviate symptoms. The biopsychosocial model illustrated summarizes the disease process (using a timeline), fixed and changeable psychological or

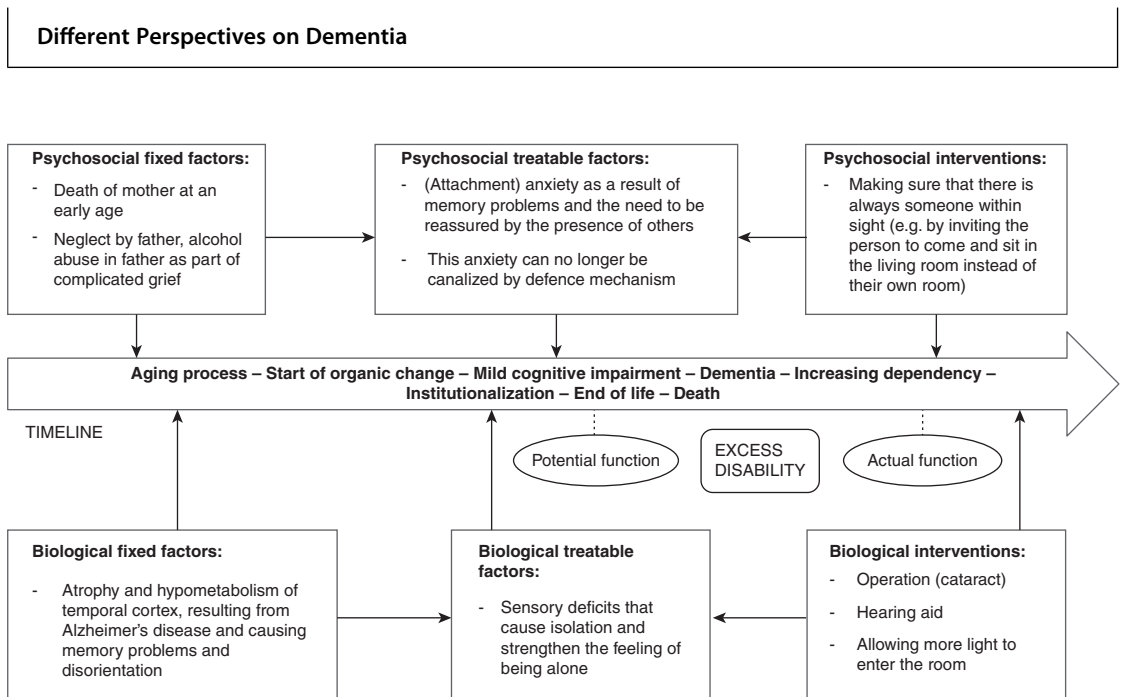


Figure 1.3 Case illustrating the biopsychosocial approach of Spector and Orrell [25]

biological factors. It encourages that dementia is recognized as something which is flexible, allowing for change, adaptation and improvement. The discrepancy between potential and actual function can be diminished, leading to less ‘excess’ disability. In some cases, this can postpone institutionalization and promote well-being. Preliminary research has already shown the benefits of applying such a model as this leads to a greater understanding of individuals with dementia and an improvement in caregivers’ abilities to develop interventions. Caregivers also report feeling more knowledgeable [26].

Obviously, many more approaches in Europe and worldwide have proven their value as interventions that successfully concentrate on the well-being of the individual with dementia and their caregivers by focussing on disease symptoms, consequences and psychosocial factors. Interestingly, there are also different psychosocial models used in dementia care, derived from more general theoretical frames, such as the attachment theory, psychodynamic models or crisis and coping models. The majority of the research on biopsychosocial models in dementia, however, involves the person-centred approach, originally introduced by Kitwood [27]. We first discuss the

person-centred approach to dementia care and then briefly describe some of the other psychosocial models that have been developed.

2.3 Person-Centred Models of Dementia

I had become the guardian not only of George’s medical history but also of the story of his life, a story that was increasingly difficult for him to articulate and of which it seemed that I alone knew many of the facts. Experiences, feelings, all kinds of memories from six decades of lived life, somehow all this had come into my keeping.

Hadas [28], p. 14

Kitwood [29] proposed an integrative and dialectical framework for dementia. In order to visualize the model, he used a simple equation:

$$D = P + B + H + NI + SP$$

In the equation, D stands for dementia, P for personality, B for biography, H for physical health, NI for neurological impairment and SP for social psychology.

There is a primary focus on the experience of an individual with dementia. In particular,

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person-centred models aim to understand how identity is formed and how it can be maintained in individuals with dementia. Kitwood and Bredin [30] believe the psychological ‘self’ has the potential to survive long into the illness. Hence, they looked at what a person with dementia needs and suggest that it is (1) *love*, (2) comfort and *trust* that comes from others, (3) *attachment* and a sense of familiarity when individuals with dementia so often feel as though they are in a strange place, (4) to be *included* in care and in the lives of others, (5) to be involved in the processes of normal life and have sources of *fulfilment* and, finally, (6) to have an *identity* related to personal history and preferences that distinguish them from another person and make them unique [27, 31].

According to Sabat and Harré’s [32] social constructionist view, there is a personal singularity, a private self, that remains intact throughout the illness despite the debilitating effects of dementia (see Chapter 3). However, there is also a ‘public’ self or selves that can be lost indirectly as a result of the illness. In particular, negative social interactions can bring forth a detrimental effect on the sense of identity and well-being of a person with dementia. Kitwood [27] also delineated 17 types of ‘malignant’ social interactions which can lead to a diminished sense of self and self-worth (see Table 1.1).

Snyder [33] illustrated how negative social interactions may impact the well-being and ‘personhood’ of individuals with dementia. She describes how patients experienced being informed about their diagnosis by a neurologist and found that many had the impression that there was no compassion, no regard for or interest in the feelings of the individual who received a diagnosis, leading to an experience of being depersonalized by the healthcare professionals rather than feeling cared for. Snyder [33] speculated that perhaps these healthcare professionals were not uncaring, but they might have been inclined to position the person with dementia wrongly as someone who, because of the illness, cannot engage in a discussion about what the diagnosis means to him or her.

Case

DOCTOR: How are you today?

PERSON WITH DEMENTIA: I am alright, but I need to get home. My children need to be picked up from school. Can someone show me the way out?

DOCTOR: There’s no need for that. Your children are at home. You are in hospital. We will take care of you.

Table 1.1 ‘Malignant’ social psychology developed by Kitwood [27]

| Type | Definition |
|-----------------|---|
| Treachery | Use of deception to distract or manipulate |
| Disempowerment | Not allowing someone to use abilities that one still has |
| Infantilization | Treating someone like a child |
| Intimidation | Causing someone to feel frightened as a result of verbal threat or physical power |
| Labelling | Referring to people inappropriately by using a term that describes and classifies them (associated with concepts of self-fulfilling prophecy or stereotyping) |
| Stigmatization | Treating someone as if they were an outcast |
| Outpacing | Providing information or asking questions/offering choices too quickly so information becomes difficult to understand or questions become impossible to respond to adequately |
| Invalidation | Not acknowledging the reality or experience of a person |
| Banishment | Excluding someone physically and/or emotionally |
| Objectification | Treating someone as an object (e.g. during washing, clothing etc.) |
| Ignoring | Talking about someone in their presence as though they are not there |
| Imposition | Forcing someone to do something |
| Withholding | Failing to provide attention or to fulfil an obvious need |
| Accusation | Blaming someone for their inability or misunderstanding |
| Disruption | Suddenly disturbing a person and interrupting their activity, speech or thought |
| Mockery | Making fun or joking at the expense of someone |
| Disparagement | Telling someone that they are worthless |

PERSON WITH DEMENTIA: I don’t need to be taken care of. It’s my children that need taking care of! Who can let me out? [Walks impatiently towards the exit and then towards the nursing station.]

DOCTOR: Has she been agitated all afternoon?

NURSE: Yes, we’ve tried to distract her, but she doesn’t want any coffee . . .

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This conversation illustrates how individuals with dementia are sometimes subtly and involuntarily excluded from conversations, not taken seriously, and hence isolated in their experience. In some cases, this means that activities are taken over unnecessarily and decisions are made for the person with dementia without involving him or her. Specifically, in this example, the doctor addresses a nurse when the person with dementia is still present and talks about her behaviour as though she was not there. She is treated as someone who needs help from others rather than as a concerned mother who wants to take care of her children. She feels misunderstood. This interaction causes further distress rather than being reassuring.

The opposite of malignant social psychology, according to Kitwood, is positive person work [27]. It consists of 12 different types of behaviours and may lead to improvement of the condition, referred to as 'rementia' (see Table 1.2) [27, 34].

One example of positive person work is recognition, which occurs when someone thanks a person with dementia, affirms his or her views or greets him or her with his or her preferred name. Another form of positive person work is play – for instance, when individuals with dementia can undertake activities that engender spontaneity, self-expression, giving and enjoyment, such as a gardening session in which they can explain to the therapist how to tend to a plant.

In line with the effect that Kitwood [29], predicted Macrae [35] found no loss of self or personhood in a small group of Canadian individuals with AD who were surrounded by supportive caregivers, with little evidence of negative social interactions. Individuals led meaningful lives and they were not concerned with the loss of their identity. Hence, indirectly, this study could support the hypothesis of how the absence of malignant social psychology and the presence of positive person work may reduce threat to the 'self' or 'selves' and promote well-being [29].

Other researchers have also looked at possibilities for strengthening a person's sense of self-worth and identity. Harrison [36], for instance, suggested that caregivers try to look at the individual with dementia within the context of this person's life, which may help strengthen a feeling of continuity and hence preserve personhood. A recent systematic review found that reminiscence and life story work – which is not restricted to the recollection of memories, but also concerns an evaluation and reappraisal of the life course – are important interventions in trying to understand a person's biography and in stimulating a sense of identity [37].

However, there are some criticisms of the personhood notion proposed by Kitwood [29] and Sabat and Harré [32]. In particular, Kontos [38] states that the body should be given an active and agential role in the constitution and manifestation of selfhood as it is a substantive means

Table 1.2 Positive person work as developed by Kitwood [27]

| | Type | Definition |
|---|------------------------|--|
| Social interactions | Recognition | Being recognized as a person with unique thoughts, feelings or preferences |
| | Negotiation | Consulting with someone about their preferences and if possible involving them in decision-making |
| | Collaboration | Promoting partnership between the healthcare professional and the person with dementia in carrying out an activity |
| | Play | Providing activities that stimulate self-expression and enjoyment |
| | Timulation/stimulation | A form of interaction that stimulates the senses (e.g. massage or aromatherapy) |
| Psychotherapeutic interactions | Celebration | Celebrating special occasions such as an anniversary or an achievement |
| | Relaxation | Offering a low-level intensity of stimulation and providing personal comfort |
| | Validation | Acknowledging someone's emotions and feelings and responding to them |
| People with dementia can take a leading role in | Holding | Creating a safe psychological space by containing distress and allowing self-revelation |
| | Facilitation | Enabling a person to do what he or she would otherwise be unable to do; stimulating the use of remaining abilities rather than pointing out errors |
| People with dementia can take a leading role in | Giving | Person with dementia presents him or herself in a positive, helpful way |
| | Creation | Individual is stimulated to be creative and offer something to the interaction spontaneously |

by which individuals with dementia engage in the world and in which agency is not derived from a cognitive form of knowledge. She refers to an ‘embodied selfhood’ that has the potential to improve dementia care when it is better understood, and hence needs to be explored further in empirical research. In a similar vein, Fazio and Mitchell [39] studied the persistence of ‘self’ in AD using visual recognition of the body. Even though individuals did not remember a photographic session that occurred a couple minutes earlier, there was an unimpaired self-recognition of themselves on the pictures taken, suggesting that the body is an essential element in the maintenance of a sense of ‘identity’ [39].

Irrespective of the definition of personhood and self, the person-centred approach to dementia has been broadly applied and it has evolved over the years – for example, the Values-Individualized approach-Perspective taking-Social environment or ‘VIPS’ framework developed by Dawn Brooker [40] and applied by Rosvik et al. [41]. There have been several literature reviews looking at commonalities in the models and practices derived from the concept of ‘person-centred care’, leading to a general conclusion that personal choice and autonomy are of great importance [42]. In the most recent review, Fazio, Pace, Flinner and Kallmyer [43] concluded that, even though there is no consistent and clear statistical proof of the impact of person-centred care, there is sufficient evidence to warrant six recommendations. First of all, it is important to know the person living with dementia as a unique person who supersedes his or her diagnosis. Second, it is important to accept the person’s reality, thereby promoting effective and emphatic communication. Third, it is important to identify and support ongoing opportunities for meaningful engagement, related to earlier or new interests and preferences, and to stimulate the experience of joy and purpose in life. Fourth, it is important to build and nurture authentic, caring relationships. People with dementia need to be connected and treated with dignity and respect. Also, it is important to create a supportive community for individuals, family and staff. This allows for comfort and creates opportunities to celebrate accomplishments. Finally, care practices need to be evaluated regularly and changed if necessary.

2.4 Psychological Adaptation-Based Models of Dementia

When models focus on individual psychology and specifically on coping of the person with dementia in order to explain behaviour or mood symptoms, they may be referred to as ‘psychological adaptation-focussed’ models of dementia.

In the psychodynamically inspired model of Hagberg [44], for instance, personality-related symptoms are considered one of the most sensitive indicators of the onset of dementia. In particular, the development of defence mechanisms is hypothesized to depend on cognitive maturation. Defence mechanisms are conceptualized as ‘mediators’ in conflicts between the individual’s needs and environmental requirements. Rather than immediately showing feelings of frustration or anxiety, as they age, individuals become more efficient in channelling conflicts between their own needs and limitations in fulfilling these needs that are induced by the environment. Cognitive development and maturity is thought to solidify these strategies and, given intact cognition, the ‘solutions’ are believed to become more and more sophisticated. As dementia primarily affects cognition, defence mechanisms will change or become inefficient. This, in turn, can become evident in behavioural changes in a person with dementia. Changes are twofold, according to Hagberg [44], as the author suggests that there may be regressive behaviour on one hand and a shift in the dynamics from a conflict-free sphere to a conflict area on the other. Lack of defence strategies could uncover anxieties that are overwhelming for the individual with dementia and have to be dealt with by family or healthcare professionals. Hence, the kind of behaviour that becomes evident as a result of failing defence mechanisms may feel childlike to the social environment.

Another model that is in essence an interactive psychodynamic model is the adaptation-coping model. This model is also concerned with understanding the person’s adaptation to the consequences of living with dementia and the influence the relationship with the social and physical environment can have on this process, in addition to personal history and disease-related factors. According to the adaptation-coping model [21, 45], which was based on the coping theory of Lazarus and Folkman and the crisis

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model of Moos and Tsu, living with dementia demands fulfilling certain adaptive tasks, such as dealing with increasing disabilities, developing an adequate care relationship with caregivers, preserving an emotional balance and positive self-image, maintaining social relationships and coping with an uncertain future. When the coping is less adequate, behavioural and mood symptoms can develop. Also, when the person is unable to cope with one or more adaptive tasks, he or she can even end up in a crisis. Support is therefore based on an individual psychosocial diagnosis which indicates the tasks and context in which the person experiences difficulties or distress, as shown by behaviour and mood disruptions and the defence and coping strategies he or she uses to maintain emotional balance. The three strategies to support the cognitive/practical, social and emotional adaptation are reactivation, resocialization and optimizing the emotional functioning, respectively. The subsequent concrete action plan consists of relevant psychosocial interventions, varying from cognitive stimulation activities, music therapy, art therapy and psychomotor therapy to reminiscence, and depends on the personal preferences and cognitive and functional abilities of the person.

A final model concerning the understanding of behaviour of people with dementia as an expression of their needs and as a manner in which they hope to fulfil these needs has been inspired specifically by a combination of ethology, psychodynamic theory and psychiatry. Attachment theory, originally conceived of by the psychiatrist John Bowlby [46] in the context of behaviour displayed by children towards their parents, was used as an explanatory model in understanding 'parent fixation' in individuals with dementia [47]. Attachment behaviour consists of all efforts to gain proximity to a primary caregiver or attachment figure in order to experience feelings of safety, warmth and security. It is especially prominent in stressful situations. Based on his clinical experience and behavioural experiments, Miesen [47] found that almost every older adult with dementia, at some point in the disease process, develops the conviction that his or her parents are still alive and some also experience the desire to find them (referred to as 'parent fixation'), leading to 'wandering' or emotionality. He interprets this behaviour as a need for security while being confronted with the many losses, disorientation

and anxiety that are the result of the disease. Interestingly, empirical research showed that a staff training in attachment theory resulted in an increased awareness of emotional needs of residents and at the same time in a reduction of anxiety and distress in these residents [48]. More in general, a homelike, familiar and secure environment seems crucial to promote well-being in individuals with dementia.

2.5 Environmental Adjustment-Focussed Models of Dementia

When the focus lies specifically on adjustment of the social or living environment to the needs of a person with dementia, models may be referred to as 'environmental adjustment focussed'. Hall and Buckwalter [49], for example, developed the progressively lowered stress threshold (PLST) model. According to them, it is important that the environment of individuals with dementia is adjusted to their cognitive as well as their functional abilities. The model distinguishes four stages in AD, each associated with different levels of stress tolerance further reducing throughout the day, and warranting a different organization of the physical and social environment. Factors that can increase distress throughout the day are fatigue, demands that exceed the capacities of the person with dementia, exposure to overwhelming or conflicting stimuli, emotional reactions to losses, physical stressors and, finally, changes regarding the caregiver, environment or routine.

Similarly, Souren and Franssen [50] emphasize that there are four different stages in AD, originally conceptualized by Reisberg et al. [51], and postulate that each stage warrants a specific approach and environment. In the first phase, there is a loss of planning and initiative, and therefore encouragement is needed. When insight, judgement and motivation reduce in the second phase of the illness, the caregivers need to intervene more actively in order to ensure safety and well-being. The third phase encompasses a loss of learned routine activities and speech, necessitating a partial taking over of activities. In the final phase, with complete loss of spontaneous motor movement, there is a complete taking over of activity.